

# Participants and health professionals' experiences with family work in first episode psychosis.

A qualitative study

Liv Nilsen, MNSc

Doctoral dissertation



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## SUMMARY

*Background:* There are few studies examining the effect of family work in first episode psychosis patients, and the studies have revealed contradicting results. Furthermore, no previous studies seem to have thoroughly explored patients', family members' and mental health professionals' experiences of participating and conducting psycho educational family interventions.

*Aims:* The purpose of the present study was to examine psycho educational family work as experienced by patients suffering from a first episode psychosis and their family members, and to investigate participant's perceived benefits of the same intervention. In addition we wanted to explore health professionals' challenges in conducting this particular intervention.

*Material and methods:* A qualitative explorative study was conducted in a natural setting. Twelve patients, fourteen family members and nine mental health professionals were interviewed. The data was analyzed by systematic text condensation, a modified version of Giorgi's scientific phenomenological approach based on Malterud's description.

*Results:* Both patients and family members highlighted the importance of the relationship with the group leaders and to meet others in similar situations. Patients experienced a high level of anxiety and tension during the group meetings and the group format was demanding immediately after a psychotic episode. Real lifetime stories told by patients were experienced as essential and helped family members understand the nature of psychosis in a way that made them able to understand and relate to the patients in a more constructive manner. The intervention was considered as important to improve the patients' social functioning. The group leaders described an intervention where the participants experienced a milieu suitable for growth and recovery. However, the group leaders described several themes that could improve the intervention. Most notably, patients still suffering from distressing symptoms and

social skills deficits need time to recover before participating. In order to reduce the patients' level of anxiety and tension during group meetings, the group leaders need to talk about these issues during the alliance meetings. The overall impression is that group leaders must have a considerable amount of knowledge, about the intervention, combined with clinical competence and experience in order to plan, recruit and provide psycho educational family work within the frames of a manual.

*Conclusions:* The study revealed several aspects that could give useful and new information in how to recruit and conduct family groups in the future, more in line with the needs of this group of participants. Group leaders need to recognize patient's level of anxiety before the intervention and to consider the different needs of patients and family members in regards to when the intervention starts. Developing insight, learning about warning signs, improving communication skills and learning to plan and solve problems are perceived as benefits of the intervention. Group leaders face challenges related to recruitment and selection of participants for family work. Awareness of these aspects would probably improve this intervention for FEP patients and their families.



## LIST OF PAPERS

The present thesis is based on the papers listed below.

- I) Nilsen, L., Frich, J. C., Friis, S., & Rossberg, J. I. (2014 ). Patients' and family members' experiences of a psychoeducational family intervention after a first episode psychosis: a qualitative study. *Issues in Mental Health Nursing*. 35(1), 58-68.
- II) Nilsen, L., Frich, J. C., Friis, S., Norheim, I., & Røssberg, J. I. (2014). Participants' perceived benefits of family intervention following a first episode of psychosis: a qualitative study. *Early Intervention in Psychiatry*. Epub 2014/05/28.
- III) Nilsen, L., Norheim, I., Frich, J. C., Friis, S., & Røssberg, J. I. (2014). Challenges for group leaders working with families dealing with early psychosis: A qualitative study. *Resubmitted to BMC Psychiatry 19.03.2015*

## **ABBREVIATIONS**

ACT: Assertive Community Treatment

DUP: Duration of untreated psychosis

EE: Expressed emotion

FEP: First Episode Psychosis

PANSS: Positive and Negative Syndrome Scale for Schizophrenia

PEMFG: Psycho educational multi-family group

RCT: Randomized Controlled Trials

STC: Systematic Text Condensation

TIPS: The Treatment and Intervention in Psychosis study

TOP: Thematic Research Area Psychosis

# 1. INTRODUCTION

Psychosis is a severe and disabling illness, which affects people all over the world, across cultures and socioeconomic groups. The severe and often long lasting symptoms cause considerable disability and it has been proposed that the illness is made worse by environmental stressors (Anderson et al., 1986). There is growing evidence that various psychosocial interventions can strengthen patients' coping strategies and protect against social stressors. Psychosocial interventions that have proved to be effective include social skills training, cognitive behavioral therapy and family work (Foults, 2006; Huxley et al., 2000). These components are present in several integrated treatment programs like assertive community treatment (ACT), community treatment services, early detections programs, and case management programs (Bird et al., 2010; Penn et al., 2005).

There are several studies examining psycho educational family work for patients who have been ill for several years. These studies show improvement in relapse rates and reduced re-hospitalizations among patients suffering from severe mental disorders (Pharoah et al., 2010; Jung & Newton, 2009; McFarland et al., 2003; Pekkala & Merinder, 2002). However, studies concerning first episode psychosis (FEP) patients are fewer and the results are contradictory. When it comes to qualitative studies there are even less studies, and to our knowledge, no one has explored psycho educational family interventions from the perspective of patients, family members and health professionals.

The goal of family work is to improve outcome and quality of life as well as to reduce family stress and strain (McFarlane & Dixon, 2003). Addington claims that psycho education in FEP need to be designed in a language and in a way that attracts young people. The improvement is more likely to happen in an optimistic milieu linked up to realistic expectations (Addington & Burnett, 2004). Interventions for families with schizophrenia have traditionally focused on coping with negative consequences of a chronic disease. The intervention, as it is designed

today, might be too demanding for patients experiencing their first episode of psychosis (Rossberg et al., 2010). Most patients suffering from a FEP are of younger age and in different life situations than those who have been ill for several years. It might be that an intervention originally constructed for another group of patients are in need of adjustment to meet the needs of young people suffering from FEP. In the present study the main purpose was to examine psycho educational family work as experienced by patients suffering from FEP and their family members, and to investigate participant's perceived benefits of the same intervention. In addition we wanted to explore health professionals' challenges in conducting a family intervention. We anticipated that to interview a group of patients, family members and group leaders could give useful and new information about how to recruit and conduct family groups in the future, more in line with the needs of this group of participants.

### **1.1. Psychosis**

Psychoses originate from the Greek words for "psyche" meaning the soul and "osis" meaning abnormal condition. The definition of psychosis has varied over the years and the concept is still used inconsistently. The narrowest definition is restricted to a break in reality testing with distortion of perception (hallucinations) or thinking (delusions) with no insight into the pathological nature of these phenomena. A broader definition includes hallucinations and delusions, even when the person accepts the experience as pathological. Schizophrenia is the most studied of the psychotic disorders. It is found universally in all cultures. The prevalence rate of schizophrenia has usually been estimated between 0.5 % and 1 % (American Psychiatric Association, 1994). Recent reviews have shown that incidence rates vary with higher rates associated with male gender and urbanity. Higher prevalence is also found in migrants compared to native-born individuals, and in developed countries compared to developing countries (McGrath et al., 2008). The etiology of schizophrenia remains unknown, but the most common view is that several factors interact to cause the illness such as an

underlying psychological vulnerability, determined by genetic and environmental factors (van Os & Kapur, 2009). Age of onset varies, but median age of onset is in young adulthood for men and some years later for women. Most patients have a longer period preceding the first episode of psychosis with unspecific non-psychotic prodromal symptoms such as social withdrawal, loss of interest in school or work, depression and anxiety (Hafner et al., 1999; Yung & McGorry, 1996). An aspect, which is assumed to have an impact on the course and outcome of the disorder, is the period from onset of psychotic symptoms until onset of adequate treatment, duration of untreated psychosis (DUP) (Melle et al., 2008; Larsen et al., 1998). A long DUP is associated with poor outcome (Marshall & Rathbone, 2011; Melle et al., 2005). The disorder is rated as one of the most costly disorders in the Western world with approximately 1 % of the Gross National budget in Norway (Johannessen, 2002). There are considerable costs due to expensive health care including medication and frequent use of health services and often lifelong disability pension. Furthermore, patients with schizophrenia may experience reduced cognitive capacity and less tolerance for stress (Mueser & McGurk, 2004; Green, 1996). However, the prognosis is heterogeneous; the disorder can develop into a severe state, fluctuate or end in partial or full recovery (Tandon et al., 2009). Treatment of schizophrenia includes antipsychotic medication and psychosocial treatment. In this thesis the term psychosis will include non-organic disorders classified as schizophrenia, schizoaffective psychosis and psychosis not otherwise specified in patients suffering from their first episode of psychosis.

### **1.1.1. First episode psychosis**

Schizophrenia and related disorders develop through phases, and the early stages include the premorbid phase, a prodromal phase, and the first episode of psychosis (McGorry et al., 2007). Psychotic symptoms mark the formal onset of a psychotic disorder (Tandon et al., 2009; McGorry et al., 2007). One in five will have a sustained recovery, and some will

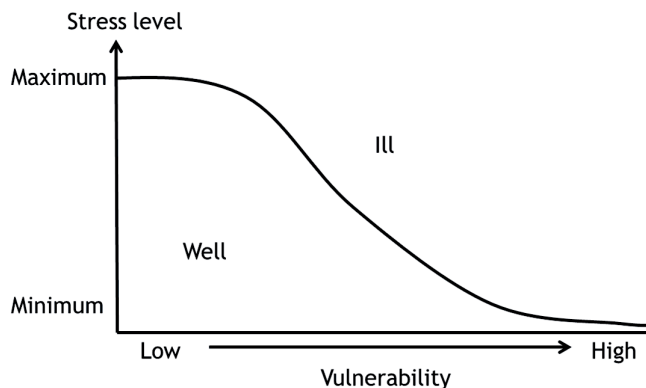
completely recover and never experience a relapse. One-third of the patients will achieve a relative good outcome with only minor symptoms and functional impairments, while the rest two thirds will have moderate to severe symptom and functional impairments (Wiersma et al., 1998). During the past 15-20 years, there has been a growing focus worldwide on identification and treatment of patients in the early phase of psychosis. These efforts were initially based on findings suggesting that early treatment and shorter duration of psychosis was related to better short-term (Penttila et al., 2014; Falloon, 1992; Loebel et al., 1992) and long-term (Helgason, 1990) outcome. Patients in areas with early detection programs, coming to treatment with shorter DUP, had significantly lower level of negative symptoms than patients outside the early detection areas; both at study entry and at two year follow up (Melle et al., 2008). In the treatment and intervention in psychosis study (TIPS) (Simonsen et al., 2007) the largest clinical and social improvement occurred within the first three months. At one year 66 % were in remission, 11 % relapsed and 23 % were continuously psychotic. At ten years follow-up, 25 % were recovered, and a further 25 % were in symptomatic remission (Hegelstad et al., 2012). The Danish OPUS specialized early intervention trial for patients with FEP found similar results. After one year of treatment there was a significant reduction in both positive and negative symptoms as well as a reduction in substance abuse, better treatment adherence, and a need for lower dosage of anti-psychotic medication, in addition to higher satisfaction with treatment and reduced family burden (Jeppesen et al., 2005; Petersen et al., 2005). After five years still a significant amount of patients in the OPUS trial were able to live independently (Bertelsen et al., 2009; Bertelsen et al., 2008). At ten-year follow up, patients in the intervention group had significantly less use of supported housing and use of psychiatric beds during the whole ten-year period compared to those receiving standard treatment (Secher et al., 2014). Early intervention in schizophrenia has two elements that are distinct from standard care; early detection and phase specific treatment. Phase specific

treatment combines psychological, social and medical treatment developed or modified for use in the early stage of the illness (Marshall & Rathbone, 2011). Some of those models also address the needs of family members of persons with mental illnesses by offering individual consultations and psycho education conducted by mental health professionals (Anderson et al., 1986; Falloon et al., 1984).

### **1.1.2. Vulnerability stress model**

Schizophrenia is a devastating illness and over the years there have been several approaches to understand its etiology and development. In the 1970s Zubin and Spring made their contribution by trying to find methods for finding markers for vulnerability in persons diagnosed with schizophrenia (Zubin & Spring, 1977). They assumed that both exogenous and endogenous challenges could cause a crisis in all humans, but depending on the intensity of the perceived stress and the threshold for tolerating stress, the crisis could lead to an outburst of the illness or not. Zubin and Spring introduced the vulnerability stress model which psycho educational family intervention used in this study is based on. The model proposes that each of us have a degree of vulnerability that under sufficiently stressful circumstances could lead to an episode of psychosis. There are two components of vulnerability, the inborn and the acquired. The inborn is described as the vulnerability that is our genetic heritage. The acquired component is due to influences such as traumas, perinatal complications, family experiences, and life events. A person with a high degree of vulnerability is likely to experience an outburst of psychosis even when they experience low levels of stress, in contrast to the one with a low degree of vulnerability that not even a catastrophic event would induce an episode of psychosis. The model is shown in figure 1.

**Fig 1. Relations between vulnerability and challenging events**



Reconstructed figure based on Zubin & Spring, 1977

The figure shows the relation between life event stressors and vulnerability. As long as the stress stays below the threshold of vulnerability the person will remain well. When the stress exceeds threshold the person is likely to develop a psychotic outburst. In this model it is important to notice that the level of stress is the individual's own perception of the stressful event that defines the severity (Zubin & Spring, 1977). During a psycho educational family intervention, reduction of stress is one of the main topics, and the environmental stress could be caused by the emotional atmosphere in the family (Brown et al., 1972).

### **1.1.3. Expressed Emotion**

In the 1950's British investigators began a series of studies that focused on the course rather than the etiology of schizophrenia. Some of these studies examined the type of living situation patients returned to after hospital discharge. Patients who returned to parental housing were found to have increased risk of relapse compared to patients who returned to other living conditions. Brown and colleagues (1972) found that the emotional climate at home could contain specific stress in patients suffering from schizophrenia. In several studies, it was



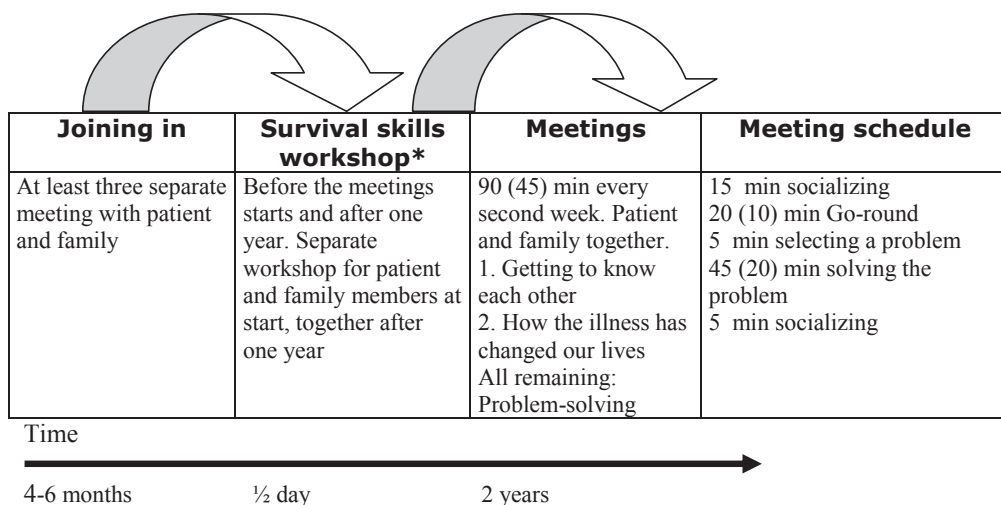
observed that high Expressed Emotion (EE) families reflected in criticism, hostility and emotional over involvement tended to have relapse rates of 50% or more during the first nine months after admission, compared to relapse rates of 13% to 15% among patients returning to low EE families (Vaughn & Leff, 1976; Brown et al., 1972; Rutter & Brown, 1966). The level of EE is measured as the extent to which a family member talks about patients with a mental illness in a critical or hostile manner or in a way that indicates emotional over involvement. Substantial empirical work shows an association between relapse and level of EE within the family (Pharoah et al., 2010; Hooley, 2007; Pitschel-Walz et al., 2001). However, research has mainly included patients with an established diagnosis of schizophrenia. Research including FEP patients shows more contradictory findings. Some studies report EE to be a relapse predictor (Patterson et al., 2000), while other studies have failed to report any association between EE and relapse (Bird et al., 2010; Gleeson et al., 2010; Heikkila et al., 2002; Linszen et al., 1996). However, it is shown that high EE families differ from low EE families in the underlying beliefs about the patient's problems and difficulties. A high EE family tends to believe that patients are more responsible for their symptoms and behavior (Barrowclough & Hooley, 2003). Barrowclough suggests that families' beliefs about the illness mediate different coping responses (Barrowclough et al., 1994). If the family attributes the behavior as controllable, they will tend to express a critical attitude to stop the undesired behavior (Barrowclough & Hooley, 2003). Vasconcelos and colleagues found that critical and over involved families behaved in different ways; critical families behaved in a direct influencing controlling manner and over involved families behaved in a more buffering controlling manner (Vasconcelos et al., 2013). Some argue that this way of coping could benefit some patients in the early stages when they are less able to take care of themselves (Jansen et al., 2014; van Os et al., 2001; Bentsen et al., 1996). There are also studies suggesting that the level of EE is fluctuating, especially during the early phases of the illness.

It might not be a trait but rather a thermometer of the patients' and family members' behavior at a difficult point of time (Patterson et al., 2000). The level of EE might be an important aspect in family work with FEP patients and their families, and will be further discussed in this thesis.

## 1.2. Psycho educational family work

Psycho educational family work is a method for working with families who have a member suffering from mental illness. The goals are to improve outcome and quality of life as well as to reduce family stress and strain (McFarlane & Dixon, 2003; Anderson et al., 1986). The method comprises three stages: the joining in period, survival skills workshop and the meetings as shown in fig. 2 below.

**Fig. 2. The structure of the psycho educational family intervention**



\* The survival skills workshop is implemented in the joining in sessions in a single-family intervention. Single-family in brackets.  
Nilsen et al., 2014 p. 59

### **1.2.1. Joining in**

Joining in is a way of working with families and patients that is characterized by collaboration in an attempt to understand and relate to the family. This is a phase where partnership is developed between patient, family and health professionals and extends from at least three sessions both in single and multi-family formats. The sessions involve both patients and family who may meet separately or together depending on the patient's condition and preferences. However, it is recommended at least one separate meeting for both patient and family so that both have the opportunity to share their experiences and thoughts without feeling intimidated or feeling the need to censor. Each session has the same structure and lasts about 90 minutes. However, the time of the sessions could be shortened if the patient has difficulties with concentration and struggles with psychotic symptoms. Each session begins with and ends with socializing which is meant to decrease anxiety, strengthen the relationship and provide information and interests outside the illness. Throughout the sessions the present crises is reviewed with particular attention to early warning signs, how the family has coped, and to explore what have been helpful or not in the past. The group leaders also explore feelings and reactions to the illness, and make a genogram where network and friends are included. Furthermore, they review past experiences with the mental health system, and identify and explore personal strengths, hobbies, work and school. At the end of the joining in phase one identifies short and long-term goals and prepare for the survival skills workshop and the forthcoming meetings. During this phase and further on in the intervention the mental health professionals are responsible to continue to be a resource for the participants as well as an advocate in dealing with other clinical or rehabilitation services.

### **1.2.2. Survival skills workshop**

The survival skills workshop was developed by Carol Anderson and colleagues, and is based on the assumption that to provide information to families experiencing severe mental illness

can help families develop realistic expectations and plans for the future (Anderson et al., 1986). The education consists of sharing information about the underlying biological, psychological and social processes of the illness. The goal is to relieve families of their guilt and anxiety so they can contribute to treatment and rehabilitation of the patient. Family members and significant others are invited to the workshop. Patients are invited to a shorter version of the workshop at a level determined by the patients' ability to tolerate and understand the information. The workshop has a classroom format with the speaker in front as this invites to a more neutral atmosphere. Anderson and colleagues (1986) have emphasized that the workshop is most effective if the information is tailored as much as possible to the actual participants. In the single-family model this format is optional, but Fallon and colleagues found that the same format could be used on an individual basis in the families' homes (Falloon et al., 1982). The workshop is usually held on a Saturday. Mental health professionals familiar with the intervention are invited to lecture about several themes in a non-blaming and easy understandable way. Several themes are being covered: mental illnesses, especially psychosis, cause and treatment, medication, warning signs, coping strategies and the main course of the intervention. This is the first time the participants meet. The two group leaders are the host of the day and are responsible for making a good and safe atmosphere for everyone. The day follows by structured education sequences with the opportunity to stop and ask questions and with long breaks with an opportunity to get to know each other. During the day, refreshments and drinks are available and a nice meal is served for lunch (McFarlane & Dixon, 2003).

### **1.2.3. Meetings**

The group meeting usually starts a week or two after the workshop. During the first two psycho educational multi-family group (PEMFG) sessions the goal is to establish a partnership between all participants. The meetings are held biweekly for 90 minutes at the

same day and time during the whole intervention, usually for a two-year period. During the group meetings the participants sit in a circle with a table of refreshments nearby. The participants might serve themselves with refreshments during the group meeting and the patients are also free to leave the room when they need a break. The group leaders are sitting opposite each other in the circle and alternate being the leader and the co-leader of the meeting. The current leader is in charge of the actual meeting and the co-leader is in charge of the manual being followed and the timetable being held. It is essential that the two group leaders are a team being able to support and strengthen each other. At the first meeting the participants are supposed to present themselves, and the leader in charge starts. This presentation is in a more open and personal way than mental health workers are used to. The intention is that everybody is partners in a mutual cooperation. The main issue is to present oneself in a positive manner, and to tell about interest and hobbies. Usually in a group, everyone can find someone with the same interests that improve their ability to be in social settings. At the second meeting everyone tells about his or her experience and the impact the mental disease has on his or her own lives. The group leaders also share their own experiences either from work or from their personal lives. This meeting is filled with strong stories and emotions. From the third meeting and onward the group format is the same. The main issue is problem solving and communication skills training. All participants are encouraged to find themes of problems and to contribute with solutions. The problems being discussed in the group are mainly from the daily life of the patients. It might be problems like attending activities, school or work, medication adherence and controlling negative attitudes. The depth and level of personal problems will change during the development of group affiliation and the feeling of security within the group. The psycho educational family intervention is based on the idea that patient, family member and group leaders meet as partners. They have a common goal to use all resources available to ease the patients' struggles in their lives. The

single-family concept is similar except for the length of each meeting and a time span of one year rather than two years. The main difference is that the discussion goes within the single family and not within a group (McFarlane & Dixon, 2003).

### ***1.3. Single and multi-family groups***

The psycho educational approach described by Anderson and colleagues (Anderson et al., 1986), family behavioral management developed by Falloon and colleagues ( Falloon et al., 1985) and the family crisis therapy model by Goldstein and his colleagues (Goldstein et al., 1978) have all been developed in a single family format and later transformed into multi-family settings. Whether to offer the treatment as a single- family intervention or as a multi-family intervention depends of the families' desires and needs (McFarlane & Dixon, 2003). However, some studies look into differences in the single and the multi-family format concerning patients with severe psychiatric disorders. In a comparative study of outcomes in community settings McFarlane and colleagues found that PEMFG were more effective than single-family treatment concerning relapse rates, 16 % versus 27 % respectively in a group of acutely psychotic patients with a mean age of 26,5 years. However, there were no differences in relapse rates for patients discharged from hospital with no positive symptoms (McFarlane et al., 1995). A replication study was designed to compare single and multi-family treatment in schizophrenia in a two years follow-up study (cited in (McFarlane, 2002, pp 53-8). In addition to the replication they evaluated the efficacy of the multi-family approach with different types of family interventions. The results showed that those participating in a single-family intervention were 60 % more likely to relapse compared with those participating in a PEMFG intervention. However, it is not possible to read out of the description of the study how many 60 % was. Superior outcome for PEMFG occurred in Caucasian patients with the most severe positive symptoms at baseline. Minority patients as African American had a better outcome in single-family interventions. However, all the studies showing superior

outcome for PEMFG had a mixture of patients with FEP and chronic psychosis, leaving it unclear to what extent superiority of PEMFG was related to chronicity. Leff and colleagues conducted a trial where families high in EE (n=12) were allocated to family sessions together with the patient, or to a relative group (n=11) without the patient (Leff et al., 1989). There were a large number of dropouts in the relative group, five out of eleven failed to attend to any of the sessions in contrast to the family sessions where the therapist visited the families at home. Due to the dropout rates it was difficult to compare the two interventions. After nine months patients who lived with relatives who attended the group had lower relapse rates than those living in families who did not attend the group. However, at a two year follow up the relapse rates were 33 % in the family therapy and 36 % in the relative group (Leff et al., 1990).

#### ***1.4. Group leader training***

Group leader training differs in length of time but is largely based on the same manual among countries around the world. In Norway group leaders participate in a 60 hours course. The training program comprises lectures and role-play of the different elements in the manual. The lectures are based on present knowledge of the illness and are presented by senior professionals. The biological and cognitive models of psychosis are the core theories in these presentations. The role-play in the PEMFG elements is carried out in small groups focusing on enhanced communication skills, following the structure, the problem solving process, education and the implementation of new knowledge and creating a warm, personal atmosphere in the group settings. The family psycho education workbook (McFarlane & Dixon, 2003) suggests that it is best to be trained by attending two or three days of skills training, including explanations, demonstrations and practice exercises followed by one year of consultation and supervision by an experienced trainer. It is also important that the group leaders have skills in teaching and keeps themselves up to date in the latest research and

evidence-based literature. The training described above is the method used in the present study.

### ***1.5. The development of family work***

It is difficult to define an exact beginning of family work. Abrahams and Veron, 1953, were the first to describe a group of girls suffering from schizophrenia who participated in a group together with their mothers. Their concerns were the mother/child relationships more than using the group as a therapeutic tool (ref in Parloff, 1961). However, since the early 1950's there have been various attempts to study interactions between family and patient with severe mental disturbances. Family work defined as a partnership between the patient, family members and health professionals started in the early 1960'. Laqueur is usually acknowledged as the pioneer of this work as he first used the concept "multi-family group therapy" (McFarlane, 2002; Strelnick, 1977). Forty years ago Carol M. Anderson described that there is considerable evidence that family variables and interactions patterns affect the duration of hospitalization and frequency of readmissions of psychiatric patients. She found it interesting that few inpatient units had treatment programs that involved families. She suggested a collaborative relationship between families and hospital staff to develop treatment that combined the acceptance of the patient's illness as the focus, but still recognized the importance of the family (Anderson, 1977). Due to the deinstitutionalized period, which started at the same time during the 1970's, Anderson, Reiss and Hogarty continued to work with family interventions and described their approach in detail to make it possible for others to make use of their work (Anderson et al., 1986). At the same time Falloon described his work with single-family interventions in England (Falloon et al., 1984). McFarlane and colleagues (McFarlane & Dixon, 2003; McFarlane, 2002) based their work on Anderson, Reiss and Hogarty (1986) and transformed the intervention into both single and multi-family group interventions. Later Miklowitz and colleagues described their family focused treatment



used in bipolar diseases and in ultra high-risk populations in the USA (Miklowitz et al., 2014; Miklowitz, 2012). Despite a wide heterogeneity, family interventions tend to be characterized by psycho education, problem solving, and family support, lasting for six months to five years (Dixon et al., 2010; Murray-Swank & Dixon, 2004; McFarlane et al., 2003; Dixon et al., 2001). The psycho educational family intervention model attempts to decrease vulnerability, improve cognitive functioning, and improve medication adherence in patients and in addition reduce family anxiety through support, structure and information about the illness. The aim is to improve quality of life by creating low-intensity environment both at home and at work in order to decrease level of stress and rates of relapse without increasing the burden in families (Anderson et al., 1986). Despite of the diversity of models, a strong consensus about the goals of family work emerged in 1998 under the encouragement of the leaders of World Fellowship for Schizophrenia and allied disorders (1998). The document summarizes the principles and rationale for family work in two goals:

*"To achieve the best possible outcome for the individual with mental illness through collaborative treatment and management."*

*"To alleviate suffering among the members of the family by supporting them in their efforts to foster their loved one's recovery."*

Since the 1970 and Carol M Andersons (1977) statement of the family as an important contributor in the mental health system, we now find the same statements regulated by law and in guidelines and recommendations in all levels of the health system in countries all over the world (Kuipers et al., 2014; Helsedirektoratet, 2013; Kendall et al., 2013; Dixon et al., 2010; Helsedirektoratet, 1999).

## ***1.6. Quantitative studies of family work in long term mental illness***

Hogarty and colleagues described a randomized controlled trial (RCT) that included psychosocial therapy in research (Hogarty et al., 1979). The study was conducted in 1976, and 105 patients diagnosed with schizophrenia participated. Fifty-five patients were randomized to treatment with a depot anti-psychotic drug and simultaneously received a daily dose of placebo tablets. The rest, 50 patients received the opposite treatment, placebo depot injections and tablets containing an anti-psychotic drug. Further, the patients were randomized into social therapy and no social therapy. Social therapy consisted of intensive individual and family social service focusing on problem solving. The psychosocial problem solving method was designed to respond to interpersonal, - personal, -social and rehabilitation needs for both patient and their family. Outcome measure was relapse rates, and at the end of the first year the rates were 40% and 35% respectively, after two years there were still no significant differences between oral and depot therapy. However, patients receiving both depot injections and social therapy had a decrease in relapse over time compared to those who received oral therapy and social therapy or no social therapy at all.

After this study from 1976 there are numerous studies concerning family interventions in severe mental illnesses. In a Cochrane review, Pharoah and colleagues estimated the effect of family psychosocial interventions in community settings for people with schizophrenia and schizophrenia-like conditions compared with standard care (Pharoah et al., 2010). All participants received family interventions at a length of six months to three years. They included 53 RCT trials from Europe, Asia and North America. The results show that family interventions significantly reduce hospital admission at one year, it may decrease the frequency of relapse and encourage medication adherence. Family interventions also seemed to improve general social impairment and level of EE within the family. However, they found no effect on drop-out rates or prevention of suicide.

## 1.7. Quantitative research of family work in FEP

Research concerning FEP and family work is scarce and the findings are contradictory. In this section, empirical studies will be described. Table 1 gives an overview of the studies.

**Table 1. An overview of quantitative research concerning family work in FEP**

Study	Rationale	Design and intervention	Outcome
Goldstein et al., 1978	Main hypothesis was that antipsychotic medication given in high doses and family treatment would improve outcome more than low doses and no family treatment Single-family	RCT 104 patients stratified into good and poor premorbid functioning for each sex. Randomized into 4 different treatment groups. High and low dosage of medication and presents or absents of social therapy together with their family.	Relapse during six weeks and at six months follow up were 0 % in the high dose/family therapy group compared to 48 % in the low dose/no family therapy group.
Rund et al., 1994	The primary research question was to examine which of two-treatment program that is most efficient in rehabilitation of patients with very early onset schizophrenia. Either a psychoeducational approach or standard care. Single-family	Comparison study 12 patients with high EE family members and 12 carefully matched controls. The experimental group received psychoeducational treatment lasting for two years.	Relapse rates were lower in the treatment group but there were no significant differences in psychosocial functioning. The level of EE changed from high to low in seven of the twelve families in the experimental group.
Zhang et al., 1994	To confirm the efficacy of family intervention of FEP patients in China. Multi-family	RCT 78 patients randomized into a family intervention group or standard care together with their family. Education and family group sessions every 1-3 month over 18 months.	Significantly lower rate of hospital readmission in the family intervention group, 15.4 % compared to 53.8 % in the control group. Longer hospital free periods, clinical status and social functioning in the intervention group.
Linszen et al., 1996	Main hypothesis was that the addition of a behavioral family intervention to the in-patient psychosocial intervention would be beneficial for patients from high EE families. Multi-family	RCT 76 patients and their families stratified into high and low EE, and randomized to patient oriented psychosocial intervention with or without family intervention.	The addition of family intervention did not reduce relapse rates for families with high EE. Low EE families became worse with the intervention.
Lenior et al., 2001	Five year follow up from Linszen' study. Multi-family	Follow-up See Linszen	Patients from the psychosocial intervention plus family intervention group stayed fewer months in hospital compared with standard intervention group.
Leavey et al., 2004	Main hypothesis was that carers who received a brief intervention package of education, problem solving advice and support at the time	RCT Randomized into either experimental g group (n=106) that received a brief family intervention comprising education and advice	Family intervention had no effect on relatives' satisfaction or service user's outcome.

	of first contact with psychiatric service would be more satisfied with care provided to their sick family member and patients would improve clinical outcome. Single-family	about the disorder in addition to standard care or to standard care (n=57).	
Jeppesen et al., 2005	The hypothesis was that integrated treatment in comparison with standard treatment would reduce subjective burden of illness, increase satisfaction with treatment, improve knowledge of schizophrenia and increase the conversion of high EE to low EE in key relatives. Multi-family	RCT 547 patients were included and allocated to either integrated treatment or standard treatment. In the treatment group 185 out of 275 patients had a family member included, in the standard care group 140 out of 272 patients had a family member included. Treatment over 18 months every other week, assertive community treatment, medication management, social skills training and PEMFG.	Significant beneficial effect on reducing burden and distress in the intervention group. No significant effect on knowledge of the illness and level of EE.
Cabral & Chaves, 2010	Examine caregivers satisfaction with PEMFG treatment and to verify if knowledge acquisition about illness and treatment was enough and understandable. Multi-family	Descriptive survey 46 patients and 65 family members were included into a treatment program consisting of medication, weekly psychoeducational and supportive therapy for the patients and weekly PEMFG intervention. After the intervention 44 carers answered a satisfaction questionnaire about the intervention.	Most of the participants found the intervention useful, organized and with time enough for discussion. Almost all believed that the meeting helped them to cope with the illness and approved the PEMFG format.
Rossberg et al., 2010	A five-year follow-up of the TIPS study. To explore if patients who participated in a PEMFG had greater improvement in symptom level, shorter duration of psychotic symptoms, fewer admissions and shorter duration of hospitalization compared to those who refused or were not offered participation. Multi-family	Follow-up A total of 301 patients were included, 147 participated in a PEMFG treatment comprising group meetings with psycho education and problem solving every other week for two years	PEMFG participants had significantly less improvement in PANSS positive and excitative symptoms, longer duration of psychotic symptoms during the follow-up period compared to those not offered or who refused to participate
Haahr et al., 2012	The research question was to what extent is patients with FEP satisfied with different treatment modalities of individual psychotherapy, medications, and milieu therapy and family intervention. Multi-family	Multi-cite project Within the 301 patients included in the TIPS study 84 was assessed for satisfaction in a self-report form measure on a 7-point scale.	75 % were satisfied with treatment in general. Individual psychotherapy and milieu therapy received higher ratings than medication and family intervention.

Goldstein and colleagues experienced that nearly half of the patients who were discharged after a short hospitalization did not continue with their medication and rarely made use of the outpatient supportive social therapy, relapsed within the first six months (Goldstein et al., 1978). They developed a study to evaluate drug interactions focused on the six first weeks after discharge. One hundred and four patients were recruited into the study and at first stratified into groups of good or poor premorbid functioning for each gender and randomized into one of four treatment groups. The groups were divided into high and low dosage of anti-psychotic medication and present or absent of social therapy together with their families. The anti-psychotic medications were administrated as depot injections. The social therapy was a six-session crisis oriented family therapy. Although there were differences in both sex and premorbid functioning, the results showed that after six weeks none of the participants in the group of high dosage and family therapy relapsed. At six months follow up still none of these patients had relapsed, compared to 48% in the low dose no family intervention group. The authors concluded that the combination of medication and crisis-oriented family therapy prevented relapses, but in order to minimize symptoms it would be useful to individualize treatment by gender and premorbid status.

Rund and colleagues studied outcome after two years of psychosocial treatment program including a psycho educational single-family intervention (Rund et al., 1994). They included 12 FEP patients with high EE family members and 12 carefully matched historical controls. Clinical outcome was measured by relapse during the two-year treatment, changes in psychosocial functioning in addition to the level of EE in family members. The number of relapses was significantly lower in the intervention group but there were no significant differences in psychosocial functioning. At start of the intervention all family members were rated as having high EE in both groups. At the end of treatment seven out of twelve in the treatment group changed from high to low EE while no one changed in the control group.

Zhang and colleagues randomized 76 male patients with a FEP to a family intervention and a standard care control group (Zhang et al., 1994). Families in the experimental group participated in regular counseling sessions focused on education in the management of the patients' treatment. After discharge the family members together with the patients attended family group sessions every three months for a period of 18 months. Patients and their families in the control group came to the outpatient department at their own request and no regular appointments were made for those who dropped out. The analysis consisted of four different treatment modalities; family intervention with medication, family intervention without medication, medication without family intervention and no family intervention and no medication. The combination of family intervention and regular medication had the best outcome and the absence of both had the worst outcome. Comparing differences between the experimental group at large and the control group they found a significant lower rate of hospital readmission in the family intervention group than in the control group (15.4% versus 53.8%). The intervention group also had longer hospital-free periods and their clinical status and level of social functioning were significantly better. Those who did not take their medication regularly and who did not receive family intervention were 7.9 times more likely to be readmitted to hospital as patients with medical adherence and family work.

In a brief intervention study, Linszen and colleagues hypothesized that an addition of family work, would be more effective with patients from high EE families compared with those from low EE families (Linszen et al., 1996). After in-patient treatment, 76 patients and their families were stratified into high and low EE and randomized to a patient oriented psychosocial intervention or to the same intervention combined with a family intervention. The results showed that patients in low EE families relapsed slightly more during the family intervention. They found that family intervention might increase stress in low EE families and thus increase relapse. However, Lenior and colleagues found in a follow up study five years

later that patients from the family intervention group stayed fewer months in hospital than patients from the treatment as usual group (Lenior et al., 2001).

Leavey and colleagues tested the hypothesis that family members who received a brief intervention at their first contact with psychiatric service would be more satisfied with the provided care and also have an impact on the patients' outcome (Leavey et al., 2004). They randomized 106 family members into either an intervention group or treatment as usual group. Those allocated to the intervention group had within six months seven sessions aiming at education, problem-solving advice and support. The treatment as usual group received support more informally and at an ad hoc basis. The drop-out rates of the intervention was high, only 24 family members (42%) completed the intervention and another 10 completed partially. There were no significant differences in satisfaction with services between the two groups at follow up, but due to the huge drop out findings are uncertain. The intervention group also complained that they would rather prefer more practical help such as assistance obtaining welfare benefits and hospital appointments.

The OPUS trial is a RCT of integrated treatment versus standard treatment in FEP. The aim was to determine whether education and intensified collaboration with general practice and social service could reduce DUP, and to investigate if a modified ACT could improve the course and outcome in young person's suffering from psychosis (Jorgensen et al., 2000).

Treatment modalities were ACT, PEMFG and social skills training. This is a large trial, 547 patients were included and of the 275 patients in the treatment group 185 had a family member included. In the standard treatment group 140 of the 272 patients had a family member included (Jeppesen et al., 2005). The treatment group had a significant beneficial effect on family members' distress related to deficits in social role. The proportion of family members changing from high EE to low EE was 63.2% compared to 59.1% in the standard treatment group. Interestingly the proportion of family members changing from low EE to

high EE were 18.7% in the integrated treatment group compared with 12.5% in the standard treatment group. There were no differences in improvement of knowledge of schizophrenia between the two groups, but satisfaction was significantly higher in the treatment group. A total of 94 family members began PEMFG treatment and 79 of those participated in six or more sessions (Jeppesen et al., 2005).

In Brazil, Cabral and Chaves conducted a descriptive survey of family members of patients with a FEP (Cabral & Chaves, 2010). They included 46 FEP patients and 65 family members into a treatment program consisting of low dose antipsychotic medication, weekly psycho educational and supportive therapy for the patients and weekly PEMFG intervention. The aim was to engage family members as early as possible in the treatment, to give information about psychosis and treatment, to acquire skills to provide home care and support for the patient, to identify the families most burdened, to facilitate the connection among families and to provide a safe and trusting environment to share experiences. Those included were invited to answer a satisfaction questionnaire about the intervention. Forty-four of the family members returned the questionnaire and most of them found the meetings useful, organized and with time enough for discussion. Almost all believed that the meetings helped them to cope with the illness and approved the PEMFG format.

Rössberg and colleagues performed an outcome study where they compared FEP patients who had participated in a PEMFG with those who refused or were not offered such treatment in the TIPS study (Rossberg et al., 2010). They wanted to explore if patients who participated in PEMFG had greater improvement in symptom level, shorter duration of psychotic symptoms, fewer admissions and shorter duration of hospitalizations during a five year follow up compared to patients who refused or were not offered the intervention. A total of 301 patients were included whereas 147 participated in a PEMFG. Contrary to what they expected the main finding was that those who participated in PEMFG had higher relapse rates, longer



duration of psychotic episodes, and higher level of PANSS positive and excitative symptoms than those not participating. Only a subgroup of families was measured on EE and most of them were low on EE. Therefore there is a possibility that low EE may have influenced the results. However, the conclusion was that PEMFG participation in FEP with a short DUP helped patients to stay in treatment, but failed to demonstrate additional therapeutic benefits. In a subsample from the TIPS project, Haahr and colleagues studied patient satisfaction with treatment in FEP (Haahr et al., 2012). They wanted to investigate to what extent the participants (n=84) were satisfied with the different treatment modalities offered in the TIPS project; individual psychotherapy, medication, milieu therapy and PEMFG. All patients received antipsychotic medication and individual psychotherapy; those in need of inpatient treatment (87 %) followed the ward milieu's treatment approach. All patients were offered PEMFG treatment and 43 % participated and attended an average of 36 meetings during two years. Overall satisfaction with treatment was highest for individual therapy followed by milieu therapy and lowest for PEMFG intervention and medication.

To sum up, few studies have examined the effect of family work for patients with a FEP. Some of the aforementioned studies have included several treatment approaches and it is difficult to disentangle what specific interventions that have been effective. Goldstein and colleagues (1978) included crisis-oriented family therapy into a drug interaction evaluation study, and the OPUS trial examined an intervention including ACT, PEMFG, social skills training and medication (Jorgensen et al., 2000). When combining different treatment modalities it is difficult to draw firm conclusions of what kind of intervention that specifically has improved outcome. Only five of the studies are RCTs (Goldstein et al., 1978; Zhang et al., 1994; Linszen et al., 1996; Leavey et al., 2004; Jeppesen et al., 2005) and some of them show that family work is an effective intervention (Goldstein et al., 1978; Zhang et al., 1994; Jeppesen et al., 2005) while some of them show no effect (Linszen et al., 1996; Leavey et al.,

2004). Two are naturalistic longitudinal studies where one shows a better outcome (patients less hospitalized) (Lenior et al., 2001) and the other worse outcome (longer duration of psychotic episodes) (Rossberg et al., 2010). Furthermore, two studies have examined family work and patient satisfaction (Cabral & Chaves, 2010; Haahr et al., 2012). Although, the two studies measure different aspects of satisfaction the results seems to go in opposite direction. Consequently, it is not possible to conclude whether family work is an effective intervention for patients with a FEP and their families.

### ***1.8. Qualitative research of family work in FEP***

There are few studies examining the qualitative aspects of family work. However, Boydell and colleagues made a general systematic review of qualitative studies of FEP patients in 2010. They suggest that psycho education contributes to recovery because it offers the opportunity for patients to better understand their illness and to find meaning in their experiences (Boydell et al., 2010). Larsen conducted an ethnographic study within the aforementioned OPUS trial (Larsen, 2007). The aim of the study was to study sociocultural process in a complex intervention by an ethnographic approach, and he used clients' reflections and insights to illustrate his findings. He used a multi-method approach including documentary analysis, individual interviews, surveys, time registration forms and written narratives. The study explored the subjective experiences of 15 patients whom he used as key informants in repeated interviews every half year during the intervention. The patients had participated in the psychosocial intervention and several of the patients did not find the family intervention useful. However, patients did describe the intervention as useful for their family members in developing a more open and supportive relationship.

A study by Lester and colleagues described FEP patient's experiences with early intervention services in the United Kingdom (Lester et al., 2011). Participants were recruited from a large multisite study, the National EDEN study, in which 63 users of early intervention service

were recruited for a qualitative longitudinal study. They were interviewed during the six months after their first service contact, and 36 (57%) were also interviewed twelve months later. The value of family support was described as crucial and during the intervention period, the family support increased. The family gained better understanding of the illness after having frequent contact with the early intervention service that gave both practical and emotional support.

In a pilot study, Eisenstadt and colleagues recruited 16 patients from a first episode program in São Paulo, Brazil to a semi structured interview concerning experiences of recovery (Eisenstadt et al., 2012). The treatment program consisted of low dose of antipsychotic medication, weekly psycho educational groups for patients and weekly PEMFG. Medication was described as necessary for improvement, and the PEMFG was a place for exchanging experiences as a start of achieving insight regarding the illness.

None of the above qualitative studies have specifically explored how the patients, their families and group leaders' experiences family work. Several questions have, so far, not been sufficiently examined, and there is a lack of empirical knowledge about when and how to tailor family work to meet the needs of patients who experience a first episode of psychosis and their family members.

## **2. AIMS OF THE THESIS**

The overall aim of the thesis is to explore how psycho educational multi- and single-family intervention are experienced by patients suffering from their first episode of psychosis, their chosen family members and mental health professionals conducting such interventions.

We had the following specific aims:

- To explore patients' and family members' experiences of the different elements of a psycho educational family intervention. (Paper I)
- To explore the perceived benefits of psycho educational family intervention on family members and patients after a first episode of psychosis. (Paper II)
- To explore the challenges faced by mental health professionals as group leaders in family interventions for first episode psychosis patients. (Paper III)

### **3. METHOD**

#### **3.1. Design**

Naturalistic methods of inquiry attempts to investigate issues related to human complexity by exploring it directly. Self-report is a widely used data collection in both quantitative and qualitative research and data can be gathered either orally in an interview or by writing in a questionnaire (Polit & Beck, 2004). The aim of this study was to explore participants' experiences, perceived benefits and challenges from a psycho educational family intervention. As the goal was to explore experiences we found a qualitative approach most suitable to answer the research questions. We chose to perform individual interviews with participants (patients and family members) and a focus group interview with health professional, with additional individual interviews.

There are several reasons for deciding upon individual interviews. First, to take care of patients who might be in a vulnerable state after experiencing a psychosis and who might be in different states of recovery. Second, we assumed that the information given in interviews would be more personal and disclose issues at a deeper level than what would be acceptable in a focus group interview especially concerning the patients. Data from individual interviews are the basis for paper I and paper II.

The purpose of the focus group interview was to listen to and gather information and opinions about challenges in conducting psycho educational family interventions in FEP. The concept of focus groups gives an opportunity to gather information from several participants at the same time. There were several reasons for inviting mental health professionals into such a format. First, the concept invites the participants to share experiences through discussions. Second, the focus is on a specific topic where several experts share their point of view and simultaneously use the group interaction as part of the method. Third the group process can

help participants to explore and clarify their views in ways that would be less easily assessable in a single interview (Kitzinger, 1995). Participants are encouraged to talk to one another, ask questions and exchange anecdotes and comment on each other's experiences. The method is useful for exploring knowledge and experiences and can be used to examine not only what people think, but also how they think and why they think that way. However, to bring several participants together requires attention to who the participants are and how the researcher will interact with the group. The focus group interview and four individual interviews are the basis for paper III.

### ***3.2. Scientific phenomenology***

Amedeo Giorgi described phenomenology as a scientific method in 1970 (Giorgi, 2000). It was introduced as an alternative to the reductionist procedures of the natural scientific approach. His description was based on an interpretation on Husserl's method which was adapted into a scientific psychological setting. According to Giorgi, phenomenological philosophy is the foundation of scientific work. Participants in research projects describe experiences of interest for the researcher from their own perspective and in their own words. In order to analyze this information the phenomenological method involves description, reduction and the search for a higher level of meaning that are essential for the context being studied. Scientific knowledge is knowledge that is general, methodical, critical and systematic. Scientific phenomenology is a method that meets all those criteria and is also to be described in a way that makes replicability possible (Giorgi, 1985). Malterud has modified Giorgi's method into systematic text condensation (STC) which is the method used to analyze data in this research project (Malterud, 2012; Malterud, 2011).

### **3.3. Interview guide**

Two interview guides (Appendix 1 and 2), one concerning patients and family members and one concerning group leaders, was conducted in cooperation with a patient who had been participating in a PEMFG a few months earlier. In addition family members both familiar to the intervention and family members asking for such an intervention, were invited to a discussion at PIO-Oslo's resource center for relatives of mental health care patients. Both patient and family members had a lot of reflections about what to ask for during the interviews and came with useful suggestions. I was familiar with the intervention and was planning to use the manual as a menu for the interviews in order to cover all phases of the intervention. After discussions with the patient and family members it became clear that it was not the process that was of importance but the substance; "what was it like to participate, how was the relation among the participants, how was it to talk about own problems in front of the others". This was an important contribution and helped making the interview guide more in line with the participants' experiences and perceived benefits. It was also experienced as useful when interviewing the health providers about their challenges in conducting such an intervention. However, after the two first interviews the interview guide felt as my security, as a document I could hold on to, to make sure that all themes of interest was covered. The interviews started by small talk followed by questions about how the intervention was introduced. After the introduction the conversation usually floated easily through the group sessions and I made follow up question often related to what other interviewees had been talking about. A few of the patients were more silent and were in need of questions framed more openly.

### ***3.4. Sampling procedure and description of the sample***

#### **3.4.1. Individual interviews (paper I and paper II)**

Patients with FEP and their family members who participated in psycho educational multi- or single-family intervention in 2010 and 2011 were eligible for inclusion. A purposeful sample, aiming at diversity of age and gender, was recruited from three hospitals in South-Eastern Norway. A total of 12 patients and 14 family members (parents/foster parents) participated and provided informed consent. One patient did not want parental participation, two patients wanted both parents to participate, and one patient preferred to be interviewed along with his mother and father due to his mother's inadequate Norwegian language skills. One patient asked to participate refused. He or she did not want to be reminded of the psychotic episode. All patients included in the study were recognized as FEP patients. The sampling was done stepwise and transcripts were done immediately after each interview. In that way the number of interviews needed to answer the research question became evident. The most important issue was to interview both patients and family members as to get experiences and perceived benefits highlighted from both angles. Demographic data as reported by the participants were collected at the time of the interview and are shown in table 2.



**Table 2. Participants' characteristics**

Patients (N=12)					Family members (N=14)				
	n	%	Range	<i>M</i>	<i>SD</i>	n	%	Range	<i>M</i> <i>SD</i>
Age	12		19-38	27	6	14		42-65	56 6
Male	5	41				6	42		
Race									
White/Caucasian	9	75				12			
Asian	3	25				2			
Education									
10 years	7	58				2	14		
13 years	2	16				1	7		
>13 years	3	25				11	78		
Diagnosis									
Schizophrenia	10	83							
Schizoaffective	1	8							
Psychosis NOS	1	8							
Housing									
Living alone	7	58							
With parents/ sheltered housing/ hospitalized	5	41							
Occupation									
Work	1	8				14	100		
School/work/ Social security	7	58							
Social security only	4	33							
Multi-family group	11	91				13	92		
Single family group	1	8				1	7		
Meetings/participation									
All	8	66				14	100		
Less than half	4	33							

\* Data as described by the participants; *M* mean; *SD* standard deviation  
 Nilsen et al., 2014 p. 61

Patients and family members were invited to participate in individual interviews structured according to an interview guide, while at the same time allowing participants to convey their experiences in their own terms. During the interview it was important to make the interview situation a good experience as possible for all participants. As an experienced clinician I am confident how to make the conversation a good experience. Still it was necessary to establish

a secure atmosphere by asking questions like: “I see you are sitting moving your legs all the time, are you tired and do you want us to finish up the interview?” or “Did I ask something inappropriate, It looks like you feel uncomfortable?” at the last quote the interviewee confirmed feeling uncomfortable, the question brought back some difficult memories. I made an apology and did my best to make sure no harm was done at the end of the interview. The health professionals were asked to keep an eye with the participants after the interview, but as far as I know, no one was in need of special caretaking afterwards. The interviews were conducted at a time and place chosen by the participants often at late afternoon or early evening. Most interviews were conducted at the participant’s own home. One patient was hospitalized at the time, and the interview took place at the ward. One patient was interviewed at my house, one patient and two relatives at my office, and one patient by phone. To be a researcher and to step into another person’s home to talk about difficult experiences requires courtesy. I as a researcher went into the interviewees’ territory and had to walk into their homes with dignity and respect. I got an impression about how the interviewees were living, but by choosing a more neutral place like a library or an office the interviewees would have been free to leave more easily during the session. I experienced that participants expected me. In one occasion, the coffee table was set, and candles were lit both at the porch and inside. In two places the mother and the father wanted to be interviewed together, they showed a sincere interest in the project and it felt not as an option to decline their wishes. The patients decided whether their close family members should be invited to be interviewed. All family members who were invited to participate accepted.

### **3.4.2. Focus group interview (paper III)**

Mental health professionals with a psycho educational family work education, with emphasis on the manual developed by McFarlane and colleagues (McFarlane & Dixon, 2003; McFarlane, 1994) were recruited from hospitals in South-Eastern Norway. Fifteen health professionals were invited for focus group interviews. Six did not respond to the invitation and four were not able to participate because of a tight working schedule. Five mental health professionals were able to participate in the focus group interview. To achieve a more heterogeneous material we decided to conduct individual interviews with the four who were not able to join the focus group interview. I made individual appointments and the interviews were conducted at their most convenient place, usually at work. The sampling strategy aimed at diversity regarding health professions, and the sample included psychiatric nurses, occupational therapists, psychologists and psychiatrists who had background as group leaders. All but one had conducted one or two multi family groups and all nine had an experience from one to 14 single-family groups. Although several men were invited to participate, all participants were women. They had five to 15 years of experience from family work. The number of interviewees was small, but hopefully the participants' long and varied clinical experience compensates for that. During the interview process it became evident that challenges experienced as a group leader was an important issue, which was easily discussed, and the material revealed interesting and unexpected answers to the research question.

### **3.5. *The researcher***

The data has emerged from interviews with patients experiencing a first episode psychosis, their family members and health providers conducting psycho educational family interventions. My position as a researcher can be described as an experienced outsider. An outsider because I have neither experienced a psychosis, nor been a close relative to someone

with this condition, and I have never conducted a psycho educational family intervention to this particular group of participants. Still, I was experienced, because I have performed the same type of intervention since 2001, to participants who suffer from severe long-term mental illnesses and dual diagnoses. I am also an experienced supervisor and have supervised group leaders performing groups from different patient populations for several years. The theoretical orientation in this study is inspired of literature about EE (Leff & Vaughn, 1985), the vulnerability-stress model (Zubin & Spring, 1977) and family work as described by Anderson, Reiss and Hogarty (Anderson et al., 1986) These aspects, have probably influenced both the data collection and the analyzing process. This means that researchers with a different theoretical framework might have found other data and categorized them in other themes than in the present thesis. The motivation for performing this study is a curiosity about how patients in their first contact with the mental health system experience the intervention. It is my experience, that this is an intervention much cared for by most participants struggling with chronic mental disorders and their family members. However, this might not be true in a population much younger and early phases of their psychotic disorder. As an experienced group leader I thought that also people with an FEP appreciated the intervention. However, after the first interview, I experienced that there were several aspects with this intervention that should be improved for patients with a FEP. I found this information interesting and explored the subject in the forthcoming interviews for all participants. Furthermore, my supervisors made an effort to reveal my preconceptions by making me explain and argue for my decisions by asking critical questions throughout the whole research period.

The study was carried out at the Centre of Competence for Early Intervention in Psychosis, and is part of the Thematic Research area Psychosis (TOP) study at the University of Oslo and Oslo University Hospital.

### ***3.6. Interviewing and transcription***

I conducted all interviews. However, in three patient and three family interviews, Irene Norheim, occupational therapist at Vestre Viken Hospital Thrust participated as a co-interviewer. Irene Norheim also participated in the focus group interview as an assistant moderator. Interviews with patients and family members lasted between 30 to 90 minutes and were conducted from August 2011 to March 2012. Interviews with health professionals lasted between 30 to 110 minutes and were conducted between June and November 2013. I transcribed all interviews. This was important as a part of the research training, but even more important because in the interview situation people meet face-to-face and more than words are articulated. The conversation is a triad where the interviewee, I as a researcher and the theme to be discussed are three dimensions that have to be conceptualized. Both interviewer and interviewee have an active role in the conversation especially since we are talking about a theme we have in common, the family intervention, but from different perspectives. By doing both the interviewing and the transcript, the essence in the interview situation was more likely to occur in the text being analyzed. It was a time consuming but important experience for me. The transcripts were done continuously in a slightly modified version (Malterud, 2011), meaning the “hms” and “yes” were not transcribed and some of the wording was changed in to a more readable version. The quotes were also written in the form that I write, dialectical peculiarities were removed and commas and periods were inserted. By doing the transcripts continuously it became evident to me that my language changed. The questions became clearer and articulated in shorter sentences, and as I became more experienced it became easier to reframe questions and check out when something seemed unclear. When I managed not to fill in periods of silence with questions the interviewees often brought in more information about issues being discussed. Even though the interview was experienced as a good situation and it felt like the participants were eager to contribute with their experience, it

was still a situation with an asymmetric relation between the interviewer and the interviewees. The participants did have something that I as a researcher would like to get hold on in order to achieve my doctoral thesis.

### ***3.7. Analysis and interpretation***

In qualitative research there are several methods being used in the analyzing process. STC aims for thematic analysis of meaning and content of data across cases (Malterud, 2012). It is suited for development of descriptions and notions related to human experience (Malterud, 2001). This study involves analyzes of experiences, benefits and challenges as experienced across several participants participating or conducting family interventions and STC was perceived as a suitable method in order to achieve this goal. STC has a descriptive approach presenting expressions as expressed by participants themselves. Most qualitative analysis implies the same steps, but is often named in different ways. In this study decontextualization, coding, synthesis, and recontextualization will be described (Malterud, 2012). Shared understanding or intersubjectivity are demonstrated by detailed description of the procedure followed to give an understanding of how data analysis was conducted and how this could lead to the results and the conclusions presented in this study (Malterud, 1993). The four stages are:

1. Total impression – from chaos to themes.
2. Identifying and sorting meaning units – from themes to codes.
3. Condensation - from code to meaning.
4. Synthesizing – from condensation to descriptions and concepts.

#### **3.7.1. Total impression – from chaos to themes**

I read through all the interviews several times to get a total impression of the material. In paper I and paper II the material consisted of 460 transcribed pages, and paper III consisted of

130 transcribed pages. After reading through the interviews several times I started to look for preliminary themes associated with the aims of the study. At this stage I read with an open mind and as far as possible to bracket my own preconceptions. The main supervisor of this research project read through all transcripts, in addition to an ongoing discussion within the research team secured that all themes of interest were identified, and not colored by my clinical experience from the intervention.

To share the understanding in how the analyzing process was performed I will give an example on how the material derived from chaos at start to synthesis at the end of the process. During the first reading themes like *Alliance and cooperation*, *climate*, *time*, *structure*, *knowledge and learning* and *support* emerged. The themes were discussed within the research team and even though some of the themes changed names several times during the analyzing process the essence of the preliminary themes, namely experiences of the participants is reflected. The process throughout the different stages of analysis will be illustrated by the theme *Climate* and how it later was transformed into *Anxiety and tension*.

Throughout the reading we became aware of the feelings the patients experienced when participating in the intervention. One important feeling was described by several of the patients namely the level of anxiety and tension before, during and after the meeting. As a first impression we named it *Climate* thinking about factors important for creating an environment for growth and development in patients experiencing a FEP. The quotes are an illustration of how it was experienced to participate in the meetings:

*"I was anxious before the meeting and felt relieved on my way home."*(Patient)

*"Worrying might be healthy up to a limit."*(Family member)

The first quote is a picture of the feeling the patient often experienced before the meeting, a feeling that for some made them more able to contribute in the group, others became more

silent than usual, although the feeling was not so unpleasant that it became unbearable.

Family members understood the necessity of this feeling up to a certain limit. The analyzing process will be further discussed in step two, three and four.

### **3.7.2. Identifying and sorting meaning units – from themes to codes**

The second step of analyzes was done with the assistance of a computerized program. Paper I and paper II by using NVivo 9 and paper III by using NVivo 10. NVivo allows one to mark all text relevant to the research question as one reads the interview transcripts, and mark each segment of text with a separate label. Segments of text can then be chunked together forming hierarchies of themes and codes. At this stage, meaning units were identified and classified related to themes discovered in stage one. A meaning unit is a text fragment containing some information about a theme or a research question. This is the process of decontextualization where data is temporarily removed from the original context, brought down to several preliminary themes, and put together across the cases being studied (Malterud, 2012). It was not possible to code every line in the material, and not all elements were important for the aim of the study. We tried to be open-minded and changed the codes several times during this process. When working in step one and two all materiel was handled in Norwegian, but meaning units were named in English.

At this stage the theme *Climate* was divided into two subthemes/codes: *To build up confidence* and *Tension in the group*.

To build up confidence denotes how the patients' ability to participate actively during the meetings was influenced by their feelings. Some managed to participate actively only in parts of the meeting and, others became more silent than usual but became more confident during the intervention.

*"Everybody else was talking so I put some pressure to myself as well." (Patient)*



Family members reported that it was easier to talk openly about their own problems when listening to participants who managed to speak openly about their difficulties. The group was described as a place to share experiences, and it felt safe, as being with old friends.

*“We care a lot for each other. I was able to tell whatever I wanted, despite of what NN (the patient) thought about the issue.”(Family member)*

The quotes describe the different feelings experienced by patients and family members, but further analyses revealed another theme. The tension the participants experienced within the group. The following quotes illustrate the differences between the two themes/codes:

*“Scary sitting in the group, I felt a dread for the first year.”(Patient)*

*“...it must have been difficult for the patients, and they hardly said anything.”(Family member)*

The family members also felt the tension not as much for their own concern but more on behalf of the patients.

### **3.7.3. Condensation – from code to meaning**

In the third step we abstracted the meaning units within each of the coding groups from step two. The text as a whole was reduced to decontextualized selections of meaning units sorted as thematic code groups across the participants. The thematic coding group describes the aim of the study in a condensed form with a text illustrating the content from meaning units. Each coding group was an analytical unit which was abstracted while we condensate the content. The same procedure is followed for each of the remaining code groups. The artificial quotations are like a working paper used as the basis for the presentation of the results. At this stage the process of translating the material into English started. Quotations in Norwegian were translated at first word by word, and then changed into more readable English but still

illustrating the essence of the interviewees. At the same time quotations high lightening the coding groups were organized in tables. This process went back and forth as an inner decontextualization/recontextualization several times to secure that the translated material was in line with the original transcripts.

The codes being used to illustrate the analysis process were transformed from quotations describing the content of the meaning units into an artificial condensate named *anxiety and tension*.

*“I felt secure having my parents there and knowing the leaders from before the intervention. At the meetings I talked a lot less than I usually did and it was difficult for the leaders to make me speak. After a while I got to know the others in the group and I loosened up a bit. I did not always dare to bring in themes that I really wanted to talk about, like parents issues. It was a strange feeling, I felt as I had a stone in my stomach and I felt both insecure and too talkative at the same time. I was anxious before the meeting and felt relieved on my way home.”*

In addition to this transformation I kept an original quote, which had the potential to illustrate the abstraction.

*“It was difficult in the beginning; it takes time to get to know each other.” (Patient)*

The same process by transforming quotations was done for all three papers. Working through the text in such a systematic way enabled us with new insight and new perspectives into the participants' experiences and made it possible to abstract the contents into a final theme.

#### **3.7.4. Synthesizing – from condensation to descriptions and concepts**

In the last step the data are reconceptualized by putting the pieces together again. We developed a story that described the findings by taking the condensates and quotations from each subgroup within a code group, and wrote a story about the phenomenon in a third-person format. To ensure that our synthesis and quotations still reflected the participant's statements we reread the original transcripts. The example illustrates how the artificial quotation in step

three was abstracted into the main theme; *Anxiety and tension* with the sub group; *Insecure-secure*.

*“When participating in a family intervention, patients and family members are supposed to expose their feelings. This can be difficult in the beginning and the level of anxiety and tension are described as a journey from insecurity to security by most of the participants.*

*Insecure - secure*

*Participate in the intervention was experienced as difficult. Insecurity was described by participants as feeling shy, being more a listener than a talker, and not being able to talk as much and as easily as they usually did. Anxiety before and during, the meeting was, for some, translated into a feeling of relief on their way home. This insecurity lasted throughout the intervention for some participants, while it became less pronounced for others. As one patient described: “It was difficult in the beginning; it takes time to get to know each other...” (Nilsen et al., 2014 p.64)*

In the final step of the analyzing process one challenge was to create adequate and precise headings. The phenomenological method involves description; reduction and the search for a higher level of meaning that are essential for the context being studied. As shown in the description of the analyzing process, names of meaning units, codes and themes have changed throughout the process as a result of this higher level of meaning given by discussions within the research group, with co-authors and with fellow researchers. The validation of the results was done systematically by comparing the full text with our synthesis and quotations to secure that it still reflected the original context. As for the STC method this is the final step of the analyzing process, however the results will be further discussed and compared with existing knowledge throughout the discussion section of this thesis.

### **3.8. Literature search**

To get an overview of the literature, a thorough search was performed at an early stage of the Ph.D work. With assistance from the librarian at the Division of Mental Health and Addiction, Ullevål University Hospital/Oslo University Hospital, searches were performed in Embase, PubMed, Ovid MEDLINE and PsycINFO databases from 2010-2015 using the following

terms: Early intervention, first episode psychosis, psycho education, family work and quantitative and qualitative research in several combinations. Throughout the research period data searches have been performed regularly to check for relevant new publications.

Bibliographies from papers have also been checked for relevant supplements.

### **3.9. Ethics**

The project was approved by the Regional Committee of Medical and Health Research Ethics (2011/566) and performed in accordance with the Declaration of Helsinki. The recruitment phase started by a formal letter to the head of the psychiatric division at three hospitals in the South-Eastern health region who approved the recruitment. At two of the hospitals a person introduced the researcher to participants willing to contribute to the investigation. At the last hospital, the researcher contacted several health professionals and asked for participants. All participants were introduced to the research project through health professionals they knew and who were familiar with the intervention. One special issue was of concern; all patients had been experiencing a psychosis and were in different stages of their recovery process. They might still be vulnerable and special attention was taken to secure that everyone was taken care of after the interview, if needed. Information about the project was given both orally and in writing several times both by those who recruited and by me in front of the interview. It was urged to give the information in an understandable and caretaking manner. An informed consent form was signed before interviews were conducted. As far as I know only one patient declined the invitation because he or she did not want to remember that part of life any more. All family members being asked agreed to participate. When recruiting health professionals the same strategy was used. They all got information about the project both orally and written and they signed an informed consent before the interview. All interviews were digitally recorded and transcribed by me. The transcripts were made anonymous and stored at a secure research server at Oslo University Hospital. The digital

interviews were stored at the same server. Coding lists and coding key was stored separately and safely locked.

## 4. RESULTS/SUMMARY OF PAPERS

### Paper 1

Nilsen, L., Frich, J. C., Friis, S., & Røssberg, J. I. (2014). Patients' and family members' experiences of a psychoeducational family intervention after a first episode psychosis: a qualitative study. *Issues in Mental Health Nursing*, 35(1):58-68.

**Objective:** To explore patients' and family members' experiences of the different elements of a psycho educational family intervention.

**Method:** A qualitative, explorative study was performed based on digitally recorded in-depth interviews with 12 patients and 14 family members. The interview data were transcribed in a slightly modified verbatim mode and analyzed using systematic text condensation.

**Results:** Six themes that both patients and family members experienced as important in the family intervention were identified: alliance, support, anxiety and tension, knowledge and learning, time, and structure. A good relationship between the group leaders and participants was essential in preventing dropout. Meeting with other people in the same situation reduced feelings of shame and increased hope for the future. Hearing real life stories was experienced as being more important for gaining new knowledge about psychosis than lectures and workshops. However, many patients experienced anxiety and tension during the meetings. The group format could be demanding for patients immediately after a psychotic episode and for those still struggling with distressing psychotic symptoms.

**Conclusions:** Group leaders need to recognize patients' levels of anxiety before, and during, the intervention, and to consider the different needs of patients and family members in regards to when the intervention starts, the group format and the patients' level of psychotic

symptoms. The findings in the present study may help to tailor family work to better meet the needs of both patients and family members.

## Paper 2

Nilsen, L., Frich, J. C., Friis, S., Norheim, I., & Rössberg, J. I. (2014). Participants' perceived benefits of family intervention following a first episode of psychosis: a qualitative study.

*Early Intervention in Psychiatry*, Epub 2014/05/28.

**Aim:** To explore the perceived benefits for patients and family members of psycho educational family intervention following a first episode of psychosis.

**Methods:** A qualitative exploratory study using data from interviews with 12 patients and 14 family members who participated in a psycho educational multi- or single-family treatment programme. Semi-structured interviews were digitally recorded and transcribed verbatim with slight modifications, after which they were analyzed by systematic text condensation.

**Results:** Patients and family members reported benefits that could be classified in five categories: i) Developing insight and acceptance requires understanding of the fact that the patient has an illness, and recognizing the need for support. ii) Recognizing warning signs requires an understanding of early signs of deterioration in the patient. iii) Improving communication skills is linked to new understanding and better communication both within the family and in groups. iv) Learning to plan and solve problems requires the ability to solve problems in new ways. v) Becoming more independent requires patients to take responsibility for their own life.

**Conclusion:** The study suggests that developing insight and acceptance, learning about warning signs, improving communications skills, learning to plan and solve problems and becoming more independent are perceived as benefits of a psycho educational family intervention.



### Paper 3

Nilsen, L., Norheim, I., Frich, J. C., Friis, S., & Rössberg, J. I. (2014). Challenges for group leaders working with families dealing with early psychosis: A qualitative study. *Resubmitted to BMC Psychiatry 19.03.2015.*

**Background:** Family work is one of the best-researched psychosocial interventions for patients with chronic psychosis. However, family work is less studied for patients with a first episode psychosis and the studies have revealed contradicting results. To our knowledge, no previous studies have examined qualitatively group leaders' experiences with family work. In the present study we wanted to explore challenges faced by mental health professionals working as group leaders for family interventions with first episode psychosis patients.

**Method:** A qualitative exploratory study was carried out based on digitally recorded in-depth interviews and a focus group interview with nine experienced mental health professionals. The interviews were transcribed in a slightly modified verbatim mode and analyzed by systematic text condensation.

**Results:** Challenges faced by group leaders were classified into six categories: (i) Motivating patients to participate, encouraging potential participants was demanding and time-consuming; (ii) Selecting participants by identifying those who can form a functional group and benefit from the intervention; (iii) Choosing group format to determine whether a single or multi-family group is best for the participants; (iv) Preserving patient independence, while also encouraging them to participate in the intervention; (v) Adherence to the protocol, while customizing adjustments as needed; (vi) Fostering good problem-solving by creating a fertile learning environment and choosing the most appropriate problem to solve.

**Conclusions:** Group leaders face challenges related to recruitment and selection of participants for family work, as well as in conducting sessions. Awareness of these challenges

could help health professionals more specifically to tailor the intervention to the specific needs of patients and their families.

## 5. DISCUSSION

### 5.1. *Main results*

In the present study the main purpose was to examine psycho educational family work as experienced by patients suffering from FEP and their family members, and to investigate participant's perceived benefits of the same intervention. In addition we wanted to explore health professionals' challenges in conducting this particular family intervention.

In paper I, patients and family members described a good relationship between the group leaders and participants as essential for preventing dropout. Meeting with others in the same situation reduced feelings of shame and increased hope for the future. Hearing real life stories was experienced as being more important for gaining new knowledge about psychosis than lectures and workshops. However, many patients experienced anxiety and tension during the meetings. The group format could be demanding for patients immediately after a psychotic episode and for those still struggling with distressing psychotic symptoms.

In paper II we found that the patients and family members perceived benefits of the intervention, was to develop insight and acceptance. They learned how to recognize warning signs, to improve their communication skills and to plan and solve problems. As a result of this new competence the patients improved their social functioning and became more independent and managed to take responsibility for their own life.

In paper III we found several challenges faced by group leaders. In the recruitment phase it was challenging to motivate and encourage participants into the family intervention at the same time as one should preserve the patient's independence. It was also experienced as challenging to adhere to the protocol and to create a good learning environment.

The following discussion will focus on nine major aspects that emerged from the three papers presented in this thesis. The nine aspects could give useful and new information in how to

recruit and conduct family groups in the future, more in line with the needs of this group of participants.

## **5.2. Discussion of findings**

### **5.2.1. The recruitment phase**

As described in paper III the recruitment phase was experienced as both demanding and time consuming by group leaders. Their clinical skills were essential to motivate patients to participate in the intervention. Patients were often reluctant to participate in a long lasting intervention and were eager to return to their ordinary lives. Family members wanted to participate as early as possible and at an early stage of the illness. They had usually been struggling for a long time and were in need to discuss how to take care of the patient at home. The divergence between the different needs of patients and family member's was difficult to handle for the group leaders. They had to acknowledge the needs of both groups. The idea behind the early intervention services is to offer optimal treatment as early as possible to promote remission and prevent relapse (McFarlane & Dixon, 2003; McFarlane, 2002). This could be questioned as it comes to involve patients in multi family work. Onwumere and colleagues suggests that not all families will be in need of intensive support (Onwumere et al., 2011), and refer to Linszen, who states that it might even be harmful for those who have a good relationship and cope well (Linszen et al., 1996). This in contrast to Bird and colleagues who argue that all families need basic support and that family work in FEP may prevent relapses and also improve engagement with services in the long term (Bird et al., 2010). In the present study, all families and patients were in need of some support, but the intervention must be individualized based on symptom severity and distress.

Expressed emotion plays an important role in family work and is discussed in paper II.

Linszen and colleagues found that patients from low EE families tended to relapse more often

than those from high EE families (Linszen et al., 1996). In contrast, the OPUS trial found that the number of families changing from high EE to low EE was higher in the treatment group than in the standard treatment group (Jeppesen et al., 2005). These contradicting findings need further elaboration. It could be that, in the future, it would be important to differentiate between those who should be introduced to single or multi-family treatment, based on the EE level in the families in the joining in phase. As, to some extent, supported by the findings in the present study it could be contraindicated to include a family with a low level of EE with too many families with a high EE level in a multi family group intervention.

Whether to recruit participants into a single or a multi-family group intervention was an important topic in both paper I and paper III. Whether the patients and families wanted a single or multi family approach was based on how many persons they managed to relate to or expose themselves to, their social skills and their level of distressing symptoms. Group leaders experienced that some patients were far too vulnerable to participate in a group and that some family members were so heavily disturbed by their own problems that it was contraindicated to offer a group intervention.

### **5.2.2. From alliance to group meetings**

In paper I the joining in phase was described as the beginning of an important relationship and the foundation for the whole intervention. However, the way from the joining in phase, to the regular meetings, were experienced as difficult, especially for the patients. The patients described it as difficult to meet others in the group meetings. This even though they had met before, at the survival skills workshop. They found it challenging to talk about their personal struggles and to expose themselves as vulnerable individuals in front of a large group of people. Family members did not find it difficult, and described the start of the meetings as a happening they had been looking forward to.

During the two first meetings the goal is to quickly establish an optimal relationship between all participants (McFarlane & Dixon, 2003). This was experienced as problematic as the patients experienced this phase as difficult. These issues are rarely described in the literature. However, it could be speculated that the transition from one sequence of the intervention (joining in phase) into a new sequence (meetings) could be difficult because it involves an acceptance of being ill. The patients, in our study, described that they wanted to go back to their ordinary life as soon as possible. They did not want to identify themselves as mentally ill. As the treatment changes from an individual level to a group level they meet others in the same situation with a psychiatric diagnosis. This reluctance to accept their own mental illness could make it more difficult for the patients to participate in the group. McGorry and Killackey state that societal stigma and self-stigmatization may act as barriers to treatment initiation for both patients and families (McGorry & Killackey, 2002). If the difficulties experienced by the patients could be understood as reluctance to acknowledge their own diagnosis, it is well worth listening to their suggestions how to make this transition less painful. In this study the patients described how to make the transition more in line with their own needs. A suggestion was to arrange a more informal meeting at start. The patients would like to meet in a social activity such as bowling, or having a pizza and an informal talk at a café, in order to make the introduction to the scheduled meetings less filled with anxiety. The group leaders were to initiate and organize the meeting, but the intention was to get to know each other and to introduce oneself to each other in an informal place.

### **5.2.3. To acknowledge the need for help**

All three papers discuss issues related to the patients' readiness to participate in the intervention. The patients experienced it as demanding to participate in a family intervention. Patients who participated did it mostly because of their families or because they were in a good healing process. Some of the interviewees dropped out of the intervention and the main

reason was that they did not see how the intervention would gain themselves. The patients believed that they would go back to their ordinary life with school, work and friends and were in no need for future treatment. In order to benefit from the intervention they had to come to terms about having an illness and that it would take time to recover. Even though the families were eager to participate they realized that the intervention could be exhausting for the patients, especially those struggling with severe psychotic symptoms. Group leaders had to navigate between the patients' desire to be a "healthy normal" and their need for treatment. This navigation has to balance between the patients need for time to acknowledge their illness and the group leaders' knowledge about how beneficial the intervention could be for the participants. Gonzalez and Steinglass claim that psycho educational family interventions should be timed to coincide with the needs of the participants, the demands of the situation and the phase of the illness (Gonzalez & Steinglass, 2002). They refer to conditions such as diabetes and cystic fibrosis, as diseases that require about two years for patients to accept. Patients suffering from FEP are likely to require the same length of time to reach a state of acceptance. Acceptance is linked to insight, and those who managed to participate in the intervention experienced a process of gaining insight and acceptance throughout the intervention and found support and hope by talking to the others in the group. There are several studies regarding the relation between insight and outcome and the results tend to point towards that better insight is associated with better prognosis (Saravanan et al., 2010; Drake et al., 2007; Saeedi et al., 2007). The study by Saravanan and colleagues found that symptoms and functioning scores improved within the first six months, whereas insight improved at a steadier rate over a 12 months period (Saravanan et al., 2010). This is in line with this study where insight and acceptance are reported to emerge throughout the intervention. Group leaders also reported challenges in their concern about how to preserve the patient's independence. In the future planning of family work for patients with a FEP,

there should be more focus on the patient's readiness to participate, and whether they acknowledge a need for help before the intervention starts.

#### **5.2.4. Knowledge about the illness**

The importance of knowledge and how to learn more about mental health are themes discussed in all three papers. All participants appreciated to learn more about mental illnesses and different treatment options, which could help them cope better with their difficulties. However, there is a difference between the needs of patients and family members. Patients experiencing their first episode of psychosis did not find the survival skills workshop useful. Some of the patients hardly remember participating and those who did, remembered how difficult it was sitting in the room together with patients they did not know. Additionally, patients are probably struggling with their concentration shortly after their first psychotic episode. Family members however, urged to get information and knowledge as early as possible, preferably long before they participated in the family intervention. Education is one of the four essential components of this intervention. The goal is to relieve guilt and anxiety so they can contribute to the treatment and rehabilitation of the ill one (McFarlane & Dixon, 2003). As knowledge increase, the tension and stress in the family decrease, and improve the quality of life for the whole family (Pharoah et al., 2010; Penn et al., 2005; Dixon, et al., 2000). Yet there is less knowledge about how knowledge improves the patient's quality of life in an early stage of the illness. Both patients and family members described the sharing of real live stories as more important than lectures. Real life stories made the family members in some way understand how it really was for the patients to be psychotic. Family members experienced a need for information and knowledge earlier than the patients. The traditional survival skills workshop does not meet this need. Thus some institutions have already regular information meetings open for all family members being interested. These regular information meetings, where the family members can learn more about severe mental disorders, could fill



some of these needs. Information and education for the patients could take place at a later phase in the recovery process.

### **5.2.5. To reduce the level of anxiety and tension**

In paper I, we described how the level of anxiety and tension influenced the patients' ability to participate during group meetings. Family members managed to understand how the patients felt and described that the meetings could be too demanding for the patients. However, they also experienced the meetings as a safe place with a lot of humor. There is limited research concerning how to create the best possible treatment environment in groups for patients with a psychotic disorder. An interesting study from the trauma field may shed light on how patients with a FEP experience sitting in a group with other people. Stige and colleagues described that trauma patients in a group intervention experienced the intervention as demanding. Furthermore continuous effort from the patients was needed if they wanted to participate. In spite of the effort the patients had to put into the intervention, they experienced that the intervention helped them to gain competence and made them able to stand more steadily in their own lives (Stige et al., 2013). Even though the psycho educational intervention is constructed to meet the needs of vulnerable patients, group leaders in the current study did neither anticipate the patients' struggles nor their anxiety participating in the intervention. It seems that FEP patients are in need of something else to ease their anxiety and tension. One way might be to prepare the patients more in the joining in phase. The group leaders should be more explicit in talking about the contents of the group meetings and most importantly discuss issues of anxiety and tension with future participants.

### **5.2.6. Improvement of communication skills**

In paper II we discussed how communication skills improved during the intervention. The skills made the participants able to bring in themes difficult to discuss. Slowly the

communication changed and the home atmosphere became peaceful and calmer.

Communication skills improved by listening and talking to others in the group, learning communication rules and positive reframing by the group leaders. However, during the qualitative interviews, no one remembered communication as an issue discussed in the group. The one exception was the focus on communication rules as a tool to structure the meeting (e.g. let only one person talk at the time, use simple words).

Family focused treatment, originally designed by Miklowitz in bipolar disorders, gives a thorough description of communication skills training (Miklowitz & Goldstein, 1990). The intervention contains education, communication-skills training and problem-skills training and is presently also being used in ultra-high risk for psychosis and FEP patients (O'Brien et al., 2014; O'Brien et al., 2009). The communication-skills training comprise the four basic communication skills recommended by Falloon and colleagues: Active listening, offering positive feedback about specific behaviors, making positive request for change and expressing negative feelings about specific behaviors (Falloon et al., 1984). This approach might be useful especially in a single-family intervention where participants could discuss and rehearse different communications techniques during the problem solving process. It might be more difficult in a PEMFG. However, some of the recommended basic communications skills are already implemented in the intervention, like positive reframing and active listening (McFarlane & Dixon, 2003), but in the future, group leaders should be more explicit about how to communicate during both the joining in sessions and at appropriate times during the group meetings.

### **5.2.7. Focus on mastery, not only problems**

In paper II the participants described how the problem-solving model was experienced as a tool to improve daily life hazards. They found the model useful, but there had to be a balance between discussing what the patients already mastered and what they experienced as a

problem in their daily lives. Addington and Burnett claim that psycho educational interventions in FEP need to be designed in a language and in a way that is meaningful for young people (Addington & Burnett, 2004). This is confirmed in a study by Lester and colleagues where users of early intervention services described the importance of offering youth friendly services and activities that made sense to young people (Lester et al., 2011). This is also in line with Grealish and colleagues who found that young people, who had experienced psychosis, indicated that perceived choice and control around treatment increased empowerment and recovery (Grealish et al., 2013). The psycho educational family intervention is originally designed to prevent relapse in patients with severe mental disorders for whom it could be appropriate to talk about and solve problems during the meetings. For the young people with FEP, it might be a better way to solve their problems by talking about what they actually manage and how they manage their challenges. They will probably experience being in more control when they use their own solutions to manage their struggles. The change will be in how to talk about problems, more than to change the problem-solving model.

### **5.2.8. How to create a good learning climate**

A good learning climate is not easy to define, it is something one feels or experiences. In paper III one of the challenges experienced by the group leaders was how to create such a climate. They experienced that the structure of the intervention made the meetings predictable and in turn made the participants more relaxed and capable to increase their knowledge about mental health issues. The competence of the group leaders was important. Their ability to create a positive and optimistic environment depended on their skills and relational competences. Ward atmosphere research shows that patients suffering from psychosis prefer a climate with high levels of support, practical orientation and order and organization and a low level of anger and aggression (Friis, 1986a). The group leaders made an effort in balancing

between structure and predictability and flexibility and responsiveness to take care of all participants. This effort was supposed to make a safe environment where patients were able to learn new skills. However, studies about perceptions of psychiatric ward environments suggest that staff member tend to view treatment environment more favorably than patients do (Friis, 1986b; Rossberg & Friis, 2004). This is in line with this study that revealed that patients were struggling with high level of anxiety before and during group meetings. This anxiety was not a central concern for the group leaders. The quality of the relationship between patients and health professionals is proposed as an important factor (Priebe et al., 2011). A good learning climate should be associated with both relational and clinical competence. The effort to create a good learning climate starts already in the joining in phase and depends on group leaders' ability to make a supportive and safe environment.

#### **5.2.9. Adherence to the manual**

Psycho educational family work is based on a manual originally made for patients struggling with chronic mental disorders. In paper III we discuss the mental health professionals' concerns about their adherence to the manual and how difficult it was to know whether they were in line with the model or not. The group leader training focused on how important it is to work within the frames of the manual. However, group leaders preferred to combine their clinical experience with the manual and wanted to work more freely. They compared this intervention with other interventions and techniques they knew and wanted to make use of their knowledge and clinical skills more freely to better meet the needs of the individual participant. However, they acknowledged the advantage of the treatment manual and that it has shown to be effective in several research programs (Lucksted et al., 2012; Dixon et al., 2010; McFarlane et al., 2003). Barlow and Greene give an overview of the pros and cons of treatment manuals (Barlow & Greene, 2001). A treatment manual gives guidance to implementation of techniques that are proven to be successful in controlled treatment outcome

studies. When health professionals implement those techniques they can be confident that the treatment they deliver will most probably be successful, and in addition the manual will broaden the clinician's strategies. Manuals are structured and they may also facilitate more efficient therapy. Further, the therapy will not be influenced by individual clinical judgment that easily could produce a worse outcome. When it comes to disadvantages the authors claims that to use manuals makes the treatment robot-like. Manuals utilized in RCT studies use to have strict inclusion criteria that restrict the group of patients. Therefore the results may have limited applicability to real world settings. Nock and colleagues describes a flexible use of manuals in real life settings (Nock et al., 2004), which is in line with the group leaders' experiences in this study. Their concerns were that the manual could easily complicate the clinical work and make it less flexible than needed if it was to be followed too strictly. Clinical skills and knowledge over a broad range of topics is essential in order to individualize the treatment to each participant. The use of the manual combined with clinical experience should be an issue in the group leader-training program.

### ***5.3. Methodological considerations***

#### ***5.3.1 Reflexivity***

A researcher does always enter the field of research with certain opinions about what it is all about (Malterud, 2001). In this research project I entered the field of research with several preconceptions. I am an experienced group leader and supervisor for the intervention being investigated. I am also a psychiatric nurse with a long clinical experience in the field of chronic severe mental disorders with strong beliefs about how beneficial this intervention is within several diagnoses. I have no experience with patients with a FEP and their families, but was quite certain that the intervention could easily be transferred also to this group. However, already in the first interview my preconceptions were challenged. The most surprising was the

level of anxiety and tension experienced by the patients sitting in the group meetings. My previous experience was that participants with a long lasting mental illness felt privileged to attend such an intervention. This finding has been important to me both as a clinician and as a researcher. It has been an issue that I have presented in several lectures and is also used to describe the analyzing process presented in chapter 3.7. It is also a finding that makes me sad. I would have liked to talk to previous participants about this important topic, and I do wonder if this is a topic of concern for most patients. As a researcher, I think this is one of the most important findings to present to other group leaders in order to prepare the patients and hopefully ease their anxiety. One other topic of concern is my supervisors. I am a female psychiatric nurse and throughout the whole research period I have had three male supervisors who are medical doctors. We have had an ongoing interdisciplinary dialogue. The intervention is conducted within several professions and the theoretical orientation of the intervention is one shared by several professions and not a specific nursing intervention. All three supervisors are experienced researchers and their competence covers all steps of the research process. Our discussions and their never ending questions about my reviews have secured that my preconceptions and previous experiences have not colored this thesis. Two of the authors in paper I and II, Irene Norheim and I, had been conducting family work and supervised group leaders for several years. We both share a theoretical approach that is consistent with family psycho education. While this may have influenced the results, the research group made a deliberate effort to bracket preconceptions in all phases of the study. Still, it is possible that researchers working with a different theoretical framework might have identified and classified themes differently than what is presented in this thesis.

### ***5.3.2 Internal validity***

Internal validity questions whether the study investigates what it is meant to investigate (Malterud, 2001; Graneheim & Lundman, 2004). One important issue is whether the decision

in how to approach the research question is the right one. The aim of the study was to explore experiences of a specific intervention, a perspective that corresponds to a choice of qualitative method (Malterud, 2011). The qualitative explorative design in the present study conducted within a natural setting gives in-depth information of a subject scarcely investigated before, and is an important contribution to future research within the same topic. A strength of this study is that there is consistency in the scientific approach and the scientific method, and the results give descriptions applicable within family work in FEP (Malterud, 2001). However, the qualitative approach gives in-depth information from a small sample of participants which gives information to obtain knowledge about characteristics, complexities and interrelationships of specific matters like experiences, emotions, beliefs and motives (Malterud, 1993). Reframing the research questions suitable for a quantitative design, for instance a self-report questionnaire, distributed to both FEP participants and those with a chronic mental illness, could give important information from a much larger population which could be generalized to a broader population than in this study.

To secure transparency the different steps in this thesis are thoroughly described and all stages are outlined as accurate as possible to help the reader to understand the process. This is done in order to make it achievable for the reader to understand the interpretation and findings to create a shared understanding of the process (Malterud, 1993). Transparency can be understood similar to replicability in quantitative research and in that way reflects the question of reliability. It is whether other scientists can follow and understand the different steps in the research process. Still a text does always involve multiple meanings and there is always a degree of interpretation when analyzing a text (Graneheim & Lundman, 2004). The interview guide was constructed after discussions with patients, family members and mental health professionals familiar with the intervention. Participants selected into the study had various experiences and different professional backgrounds that increased the possibility to

shed light of the research question from different angles. Credibility concerns how well data and the analyzing process attends what it is supposed to attend and the amount of data necessary to answer the research question in a credible way varies (Graneheim & Lundman, 2004). During the interviews an interview guide was used to secure that all questions concerning the intervention was covered (Appendix 1 and 2). In addition follow up questions were necessary due to new insight in the process and to narrow the focus of the study. I did all interviews and the transcription, the transcription was done immediately after each interviews. This gave an overview of the material and an answer to when saturation was reached. To secure that the research findings deals with categories and themes that cover data and that relevant data has not been excluded or irrelevant data included (Graneheim & Lundman, 2004), the research group actively discussed all stages of the research process and explicitly the analyzing process until consensus was reached. Even though multiple realities exist the discussion within the group was important. Another issue to verify the data has been to seek agreement among colleagues, experts and participants, and by participating in conferences and in research meetings throughout this research period. However, by performing the interviews and the transcripts continuously we were able to control the information and are confident that despite the low number of participant we secured saturation. In paper I and in paper II the time between the end of the intervention and the data collection (interview) varied between one and 12 months. This time span might have influenced patients' and family members' perception and experiences with the intervention. This mostly due to recall bias and the fact that patients, as time goes, might remember more positive than negative experiences. The research coordinators who asked patients to participate could also have influenced the sample. They might have asked patients to participate who were more likely to say yes than no. It is only known that one patient asked to participate said no because he or she did not want to remember that part of his life. The patients and family members who agreed to take



part in this study were probably more motivated and capable of participating in such a program than the average patient and family. Only one family participated in a single-family intervention. However, removing this case from the analysis had negligible impact on the main results. It is also important to note that both patients and family members discussed both pros and cons by participating the one or the other group format, and had a clear opinion about which format they preferred. In addition we interviewed both patients and family members, and were thus able to elucidate perspectives of the same phenomena for different stakeholders.

Paper III has a small sample size, but the long and varied experience of participants should compensate for that. Although several men were invited to participate in the study, the sample consists only of women, and the sample may therefore be associated with gender bias. It could be argued that if some men were included, the results might have been slightly different. Still, the challenges our participants report is not specifically related to gender and was not highlighted in any of the interviews in the study.

### **5.3.3 External validity**

External validity questions the transferability of the results, meaning whether or not the results can be applied in another setting (Malterud, 2001). Variation concerning gender and a mixture of participants who fulfilled the intervention and who dropped out (papers I and II) and the variation of health professions (paper III) strengthens the external validity of this study and was of concern when planning the study. We will argue that the results due to the varied sample of patients, family members and mental health professionals could be transferred to other FEP groups in the western world participating in the same intervention (McFarlane & Dixon, 2003). It is important to notify that the transferability of the intervention does not necessarily include other mental health disorders in other populations. However, the wide variance of the information gained in this study is much broader than

anticipated at start and are likely to concern other populations as well. Such a view is in line with Marshall and Rathbone who suggests viewing the result in a broader context since family therapy is known to be useful for people with a long lasting schizophrenia (Marshall & Rathbone, 2011). It is also confirmed by Stige research in trauma clients (Stige et al., 2013), and by a study about the same intervention in brain injury patients, which revealed many of the same experiences and benefits as described in this study (Couchman et al., 2014). The results may not be transferable to all participants with FEP, but knowledge about the results might be of importance to help group leaders to avoid some of the pitfalls in facilitating the intervention.

## 6. Clinical implications

The results of this study have several implications that could improve the intervention and thus be important for clinical practice.

1. Provide family treatment as early as possible. Both patient and family members are in need of information and education as early as possible, but a lot of family work can be performed a long time before one gets invited into a psycho educational family intervention which is an advanced form of intervention.
2. Differentiate between those who should be introduced to single or multi-family treatment by the whole families' social function and the patient's level of distressing symptoms.
3. Arrange an informal social meeting in front of the regular meetings. A meeting initiated by group leaders for patients to get together and have a look at each other and introduces oneself for each other.
4. Investigate if the patients have reached a state of acknowledgement of the illness before they get invited into this intervention.
5. Tailor the first survival skills work shop to individual needs.
6. Discuss the level of anxiety and tension often experienced in the group during the alliance period. Make individualized strategies to ease this anxiety.
7. Be more explicit about communication techniques during the whole intervention
8. Group leaders need to be trained to create a safe and supportive learning climate.
9. To what extent clinical experience can justify less strict adherence to the manual should be an issue in the group leader-training program.

### **6.1. *Implication for further research***

Results from the study described in this thesis suggest that the psycho educational family intervention needs adjustments for patients with FEP. First of all there is a need for a new manual describing the desired changes. Afterwards it could be interesting to investigate, in another qualitative study, whether such adjustments would improve the intervention.

Hopefully an adjusted intervention would turn out more beneficial for FEP patients.

Moreover, one could investigate differences in single and multi-family groups after the changes have been performed.

Expressed emotions are also a field of concern. This study reveals that the level of EE in families might be one of several factors when recruiting participants into the intervention. It would be interesting to design a study to investigate the relationship between level of EE and satisfaction with the intervention both in patients and in family members.

It could also be interesting to perform a longitudinal study and follow participants over time to get more insight into the dynamics of individual experiences and processes in groups.

## 7. CONCLUSIONS

Psycho educational family work either performed in a single or a multi-family format is an intervention originally designed for people suffering from severe, chronic mental disorders. However, the intervention is widely used in the FEP population as well. The findings of this study support previous theories and recommendations. Participants find the intervention of high quality, and experience to be taken care of in a milieu suitable for growth and recovery. However, this thesis indicates several opportunities for improvement that group leaders should take into consideration when they recruit and provide the intervention in FEP. Patients experiencing their first episode of psychosis and their family members are in need of family treatment at an early stage of the illness. However, this specific intervention is described as an advanced form of treatment and could be too demanding. Patients still suffering from distressing symptoms and social skills deficits need time to recover before participating. The same could be the fact for those patients who have remitted and do not see the point in participating in such a long lasting intervention. The patients in our study described their urge to go back to their ordinary life as soon as possible. They did not want to identify themselves as mentally ill. There should also be a differentiation between those who should be offered single or multi-family intervention. Patients who struggle with severe and distressing symptoms and families with poor social functioning could benefit from a single family intervention compared to those with minor symptoms and a higher level of social functioning who more easily could participate in and benefit from a multi-family group format. To gain knowledge about the illness is experienced as crucial. However, patients do rarely remember the first survival skills workshop and suggests a more informal meeting in front of the group meeting in order to be introduced to each other. Patients also report a high level of anxiety and tension during group meetings and this should be an issue to discuss during the alliance

meetings to make individualized strategies to reduce this feeling. Participants perceive improved communication skills, but do not realize that it is an important element in the intervention. Group leaders should be more explicit about how to communicate during sessions and when they use communication skills techniques in order to teach the participant new tools in communication. The overall impression is that group leaders must have a considerable amount of knowledge about the intervention combined with clinical competence and experience in order to plan, recruit and provide psycho educational family work within the frames of a manual. The findings in the current study are of importance in improving family interventions for patients with a first episode psychosis. Family work should be an integrated part of an individualized treatment program for patients experiencing a first episode of psychosis.

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# APPENDIX

## Appendix 1: Intervjuguide for pasienter og familiemedlemmer.

Generell introduksjon med gjennomgang av informasjonsskriv og samtykke skjema som signeres av både informant og forsker.

Kan du fortelle litt om deg selv?

Oppfølgingsspørsmål om det ikke kommer frem i samtalen: Alder, kjønn, sivil status, utdanning, arbeid, familie og tilhørighet, bolig.

Hva gjør du til daglig?

Når kom du i kontakt med helsetjenesten for første gang?

Fortell litt om hvordan du/ familiemedlemmet ditt fikk diagnosen.

Har du deltatt i en enfamilie eller flerfamiliegruppe?

Hvor mange møter har du deltatt i?

Erfaringer fra et psykoedukativt familietilbud.

- Hva var det som var avgjørende for at du takket ja til tilbudet?
- Hva tenker du om den informasjonen du fikk før du takket ja til tilbudet?
- Kan du beskrive hvordan den første tiden du gikk i familiegruppen var?
  - Dette er en periode som vanligvis kalles allianseperioden, en periode hvor du skal bli kjent med de som leder behandlingen og får mer informasjon om hva tilbudet går ut på. Hvordan var det for deg?
  - Synes du at du ble kjent med behandlerne?
  - Var den informasjonen du fikk god nok?
- Etter at perioden med å bli kjent var over begynte familietilbudet. Kan du beskrive hvordan du opplevde det?
  - Møtene
    - Ble det for mye informasjon?
    - Hvordan var det å sitte i møtet?
  - Undervisningen
  - Problemløsningsmetoden
    - Hvordan var det å snakke om egne utfordringer?
    - Når dere løste problemer var det en balanse mellom problemer og muligheter?
  - Strukturen på møtene
- Kan du beskrive hvilken nytte har du hatt av dette tilbudet?
- Det å få en psykoselidelse oppleves av mange som en stor krise. Denne krisen kan føre til at du får nye behov som du trenger hjelp for å mestre.
  - Kan du beskrive om du har opplevd slike behov?
  - På hvilken måte opplevde du at disse behovene ble ivaretatt?
- Er det noe ved dette tilbudet som du tenker burde være annerledes?
  - Struktur på møtene

- Varighet av familietilbudet
- Gruppe eller enfamilietilbud.
- Var noe ved tilbudet som har hjulpet deg til å mestre dagliglivet på en annen måte?
  - Få råd og støtte fra andre.
  - Lære en konkret måte å løse problemer i hverdagen på.
  - Få kunnskap om varselsignaler og psykisk lidelse.
  - Få hjelp til å redusere eller øke aktivitetsnivå ut fra hvordan du har det psykisk.
- Hva var det med tilbudet som bidro til at du hadde lyst til å møte opp?
- Hva var det med tilbudet som bidro til at du ikke møtte opp?
- Hva kan gjøres annerledes for at tilbudet skal passe deg bedre?

#### Familie/nettverk

- Hvordan var det å ha møter sammen med familien din?
- Hvordan fikk dere hjelp til å få det bedre sammen?
- Har dette tilbudet hatt betydning for hvordan dere snakker sammen i familien?
- Har dette tilbudet hatt betydning for det sosiale nettverket ditt?
- På hvilken måte har dette hjulpet deg til å være sammen med andre mennesker?

#### Egen helse

- Hva er det som gjør at du/ditt familiemedlem har det bra?
- Hva kan bidra til at du får det dårlig?
- Hvordan har dette tilbudet hatt innflytelse på hvordan du takler de problemene du har hatt?
- Har ditt syn på psykisk problemer endret seg etter dette?
- På hvilken måte har dette tilbudet påvirket det livet du lever i dag?
  - Hvis du opplevde bedring. Hva var det som bidro til det?
- Hva skulle du ønske at psykiatrien/hjelpeapparatet kunne tilby slik at du og din familie kunne få det bedre?
  - Hva må til for at det skal bli noe av?

Takk for deltakelsen!

## Appendix 2. Fokusgruppeintervju for behandlere.

Generell introduksjon med gjennomgang av informasjonsskriv og samtykkeskjema som signeres av alle deltakerne.

Det informeres spesielt om at dette er en samtale rundt et psykoedukativt enfamilie/flerfamilietilbud. Det er ingen svar som er riktig eller gale og om deltakerne i gruppen har ulike opplevelser og erfaringer vil det gi et nyansert bilde av behandlingen. Intervjueren skal sørge for at diskusjonen flyter og kan bidra med utfyllende spørsmål, men ikke selv ta del i diskusjonen.

Først har man en introduksjonsrunde hvor alle deltakerne presenterer seg.  
Alle fyller ut skjema med demografiske data

Erfaringer fra et psykoedukativt familietilbud

- Kan dere fortelle om hvordan dere opplever dette familietilbudet.
- Behandlingen er oppdelt i faser, kan dere beskrive hva dere tenker om de ulike fasene.
  - De innledende møtene hvor tilbudet presenteres og en blir kjent med hverandre.
  - Undervisningsseminar for pasienter og familiemedlemmer. Både ved oppstart og etter et år.
  - Møtene
  - Avslutningsfasen
- Hvilken nytte tror dere pasientene har hatt av familietilbudet?
- Er det noe spesielt ved tilbudet som bidrar til at deltakerne møter opp?
- Er det noe spesielt ved tilbudet som bidrar til at deltakerne ikke møter opp?
- Hva tenker dere bør endres på for at tilbudet skal passe bedre til personer med en nyoppdaget psykose og deres familie?

Hvis dere skulle beskrive en som faller ut, hva vil dere si da?  
Hva tror dere kan ha spilt inn?

Før intervjuet avsluttes:

Informasjon om prosjektet videre, hvordan dataene skal behandles. Avklare hvordan informanten kan få tilbakemelding om prosjektet og mulighet for å ta kontakt om man er i tvil om meningsinnhold etter at intervjuet er skrevet ut.

Takke for deltakelsen